

A CAREGIVER'S DECISION-MAKING PROCESS IN REMAINING ENGAGED IN A
LEAD FOLLOW-UP PROGRAM WITH A CHILD WITH AN ELEVATED BLOOD LEAD
LEVEL

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Keywords: Grounded Theory, treatment engagement, decision making in treatment, nursing

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Abstract

Lead is a systemic toxicant without health benefits or safe exposure level. In 2006 there were 24.7% children under the age of 6 years, or 6.9 million who had blood lead levels between 2-10 µg/dL. Nearly 1.4% of children, who considered lead poisoned with a lead level greater than 10 µg/dL. The effects of lead are irreversible and even chronic low levels have resulted in reduced intellectual quotient, shortened attention span, hyperactivity, learning disabilities, and other lifelong health problems. Once a child has an elevated level they must participate in ongoing follow-up services including frequent blood lead testing, hazard control, case management, environmental inspection, parent lead education and dietary counseling.

It is imperative that caregivers and children remain engaged and this process includes home visits, repeated follow-up lead testing until lead levels fall below the level of concern. A study examined the time it took for lead levels to drop below 10µg/dL and found that almost 46% of the children in this sample were not used in the final study because they were lost through attrition. A literature review revealed there is little research on the caregiver's experience with lead follow up screening.

A qualitative study using grounded theory methodology was undertaken to generate the beginning of a substantive theory on decision making processes caregivers to remain engaged in lead follow-up screening program and the social contexts and processes that influence this decision processes. The aspects of this process are described by caregivers as *Psychological Reactions, Parental Coping and Meeting Expectations*. The in-vivo core concept, *Tells you if what you are doing is working* was a common phrase used by caregivers describe the purpose of lead follow-up screening. Families were not engaged but were trying to meet expectations. Meeting expectations, as their obligation as caregiver and to avoid medical neglect.

Interventions such as shared medical appointments would improve support and outcomes, clearer communication and management of non-negotiables is important to maintain therapeutic alliance with nurses. Training on family assessment and point of stress interventions are necessary so nurses can assist to improve family coping.

Keywords: Grounded Theory, treatment engagement, decision making in treatment, nursing

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List of Abbreviations

Abbreviation	Term
ACLPP	Advisory Committee Childhood Lead Poisoning
ADHD	Attention Deficit Hyperactivity Disorder
BLL	Blood lead level
CDC	Center for Disease Control and Prevention
CLPPP	Childhood Lead Poisoning Prevention Program
CPA	Continuous Partial Attention
CPI	Consumer Price Index
ELL	Elevated blood lead level
EPA	Environmental Protection Agency
GT	Grounded Theory
EWCSDP	Early Well Child Screening Diagnostic Prevention
HCP	Health Care Professional
HD	Health Department (State of Kentucky)
HHS	US Department of Health and Human Services
II	Income Index
KYCHFS	Kentucky Cabinet of Health and Family Services
KYCLPPP	Kentucky Childhood Lead Poisoning and Prevention Program
LFS	Lead Follow-up Screening
LFU	Lost to Follow-up
LHD	Local Health Department
LPRI	Lead Poisoning Risk Index

Abbreviation	Term
MNT	Medical Nutritional Therapy
MRI	Magnetic Resonance Imaging
MRS	Magnetic Resonance Spectroscopy
PI	Prevalence Index
SMA	Shared Medical Appointment
SI	Symbolic Interactionism
USD	United States Dollars
WIC	Woman, Infant, Children Nutritional Services

Chapter One: Introduction

This researcher established the case management program and worked as a case manager in a Childhood Lead Poisoning Prevention Program (CLPPP) for two years. During this time many of the families who had children with elevated lead levels (ELL) were very concerned about the health of their child and willingly participated in their child's care to reduce their ELL. Caregivers would participate in home case management, environmental visits, return for lead follow-up screening (LFS) and discuss ways in which they could modify their child's living environment and whether they could re-locate and/or approach landlords for interventions on the home. Over time some families became lost to follow-up (LFU) and did not return for LFS, were not contactable, and as a result did not return for Woman Infant Children nutrition services (WIC) as it is a service which is also offered in the Health Department. Later while working on another project this researcher had contact with a mother who had become LFU who spoke of the futility in trying to change the environment and the fear that she would lose her children if she could not modify the living environment and thus lower her child's blood lead level (BLL). This mother indicated that over time and after multiple contacts with the Health Department, case manager, health care providers and contacts at the State Health Department her solution was to become LFU and thus not contactable by the very people who were charged to help her. She spoke of weighing her options and trying to make the decision between taking her children in for testing and knowing what their lead levels were or keeping her family intact by avoiding follow-up (Dinsey-Read, 2006). These glimpses into the lives of caregivers and the decisions they had to make to manage their children's health and lead follow-up screening while holding their families together prompted this researcher to look more closely at this issue.

A search of the literature revealed only two articles that explored LFS process. Moodie, Tsui and Silbergeld, (2010) considered community and family level factors that influenced caregivers to screen their children in a superfund mining site. The mining community screens all children, 18 years and under for ELL, and completes follow-up testing year to year, because of the significant exposures to mining and smelter lead sources. Another study determined the proportion of Michigan's Medicaid-enrolled children aged 6 years or younger, who had a screening that was elevated and then received the required LFS within the required 180 days (Kemper, Cohn, Fant, Dombkowski & Hudson, 2005). Literature could not be found that explored caregiver's perceptions of LFS, the decision-making process to remain in the program, or the social processes or contexts that influenced caregiver's decisions to remain engaged in a LFS program.

Background

Lead is a systemic toxicant with no health benefits and with no safe exposure. Lead poisoning affects approximately 1.4% of US children between the ages of 1-5 yearly (Jones et al., 2009). In the 2007-2010 National Health and Nutrition Examination Survey (NHANES) cycle the percentage of children between ages 1-5 years of age with BLL at or above 5 µg/dL was 2.6% (US Department of Health and Human Services [HHS], 2012). The effects of lead poisoning are irreversible and can cause damage to the central nervous system resulting in lower IQ, learning disabilities, hearing loss, hyperactivity, impaired growth, seizures, and coma. Lead poisoning usually has no symptoms and often goes undetected and untreated (Center for Disease Control and Prevention [CDC], 2004).

Lead affects almost every system of the body and is ingested most commonly through swallowing small invisible lead dust particles. Lead mostly impacts children under the ages of

six as it is easily absorbed into their bodies and interferes with the normal growth and development of their brains and organs. Children under the age of two are at the highest risk for the effects of lead and readily absorb up to 50% of the lead they are exposed to while adults only absorb 10% (Alliance to End Childhood Lead Poisoning,[ACLP], 1999;Cohen, 2001). Children are at the greatest risk for lead poisoning when they live at or below the poverty line and reside in older housing (CDC, 2009). Children of some racial and ethnic groups, who live in older housing, are disproportionately affected by lead (CDC, 2009). Up until 2012 a child was lead poisoned with a BLL greater than 10 µg/dL; BLL of 15-19 µg/dL was considered moderate, and the level of 20-44 µg/dL was considered high. Levels that are 45 or higher are considered very high (Koplan, Richard, McGeehin, & Noonan, 2002). Research demonstrated that even long-term exposure of very low levels had life long health impacts, so the blood lead level of concern is now 5 µg/dL. The change in this value has resulted in even more children being identified as having lead exposure (CDC, 2012).

Canfield et al., (2003) studied 172 who children had BLLs measured at 6, 12, 18, 24, 36, 48, and 60 months and had the Stanford-Binet Intelligence Scale at the age of three and five years of age. The results of this study indicated that the effect of blood lead concentration was inversely and significantly related to IQ. A linear model found that an increase in 10 µg/dL in BLL resulted in a 4.6 decrease in IQ ($p=.0004$). This study also found BLL had a much greater impact proportionally on I.Q at lower levels of lead concentrations. An analysis found that a loss of 7.4 IQ points for a lifetime had an average BLL concentration of up to 10 µg/dL (Canfield et al., 2003).

Multiple sources of lead exist throughout the environment. The largest source of lead is found in homes that were built before 1978 and painted with lead-based paints. Lead dust results

from renovations and paint deterioration over time. In the United States 24 million housing units have lead based paint with house dust that contains lead levels that are at greater than the acceptable level. Of these homes, 4 million have young children living in them. It has been estimated that approximately 83% of all housing units built in the US before 1978 have lead based paint on the exterior or interior (CDC, 2004).

Statement of the Problem

Lead screening programs are the primary method in which ELL are found in children. Children with BLL between 10 to 30 $\mu\text{g}/\text{dL}$ presents without symptoms or abnormalities during medical history, physical examination or lab test apart from the ELL (Koplan, Richard, McGeehin & Noonan, 2002). Children identified with ELL require frequent blood lead testing follow-up, lead education including environmental lead hazard control and dietary counseling. Home visits include environmental investigation, case management, and a referral for nutritional services (Advisory Committee on Childhood Lead Poisoning Prevention [ACCLPP], 2000).

In their role as lead clinic nurses, public health nurses, spoke of the difficulty of getting caregivers to return with their child for lead LFS and the barriers that they believe existed for this group for follow-up (Dinsey-Read, 2008). Nurses indicated that lead screening and WIC services were conducted in the same clinic and often if parents missed an LFS appointment they would stop attending their WIC appointments entirely. This was very concerning to the nurses because not only were the children's BLL elevated, but their nutritional status was also being compromised (Dinsey-Read, 2008). The nurses' concerns are supported by observations of the Kentucky state CLPPP director, who indicated that LFU is a concern especially in the counties with high lead hazards and are urban regions of the state (Susan Lawson, personal communication, April 16th, 2012).

Further communication with the nurses revealed caregivers were worried that they would lose their children. Other caregivers did not believe that the Health Department (HD) should have access to their home and that the condition of their child was a personal family matter not one of the State (Dinsey-Read, 2008; McGee, 1999). Families reacted in many ways to learning their child was lead poisoned. Caregivers often became defensive believing that they were being accused of not being clean. Others felt that the HD was interfering in their lives and that they might lose their children. The nurses spoke of families who avoided the HD, not returning for WIC appointments after failing to follow-up with lead retesting. Parents expressed frustration about trying to manage the living environment of their child and lower their child's BLL. They often tell the nurses that they are 'good parents' because they really want the nurses to know this. The nurses attempted to use many different strategies to get parents to return for WIC appointments and comply with testing with limited success (Dinsey-Read, 2008). To date there is a lack of data about the decision-making process caregivers use to remain engaged in an LFU screening program, taking into consideration the social context and processes that influence their decisions.

Statement of Purpose

The purpose of this study was to generate the beginning of a substantive theory on caregiver's decision-making process that determine continued engagement in lead follow-up screening.

Research Questions

1. What are the decision-making processes caregivers undergo to determine if they will remain engaged in the lead follow-up screening program?

2. What are the social contexts and processes that influence the decision-making processes that caregivers undergo to determine continued engagement in a lead follow-up screening program?

Significance of the Study

Children with ELL require LFS to ensure that BLLs continue to decrease and that the lead hazard reduction strategies have been properly identified and controlled. Caregivers with children who continue with ELL need to have: 1) assessments of the child's behavioral development changes which may have increased their access to lead hazards; 2) assessment of the living environment for lead hazard control and; 3) participation in health-orientated interventions: education for controlling lead hazards, nutritional medical therapy, WIC, and Medicaid. In some cases, the child may require referrals to specialized lead and developmental clinics in the regional Children's hospital for more aggressive management. Failure to return for LFS results in these important interventions not being instituted and the elevation of BLL to continue unchecked (ACCLPP, 2000). The implications for these children are a loss of life time educational potential and individual productivity.

The negative impact of lead on child development, behavior, IQ, and other health concerns have been well documented and research has also demonstrated that even chronic low lead levels of 2 µg/dL can having serious lifelong implications (Alliance to End Childhood Lead Poisoning, 1999; Canfield et al., 2003; Cecil et al., 2001; Chen et al., 2007; Cohen, 2000; Gemmel et al., 2002; Lanphear et. al., 2000; Roy et al, 2009; Selevan et al, 2003; Wright et al., 2008). The estimated cost for lead poisoning treatment is \$ 5.9 million with an estimated additional \$50.9 billion loss in economic productivity from reduced cognitive potential (Trasande & Liu, 2011). This estimate does not include the cost of special education that in 2006

was estimated to be \$ 14,317 per child or between \$ 30-146 million for each cohort of lead poisoned children (Gould, 2009). The cost of treatment for attention deficit disorder (ADD), which has been linked to BLLs greater 2 µg/dL, is \$ 267 million annually (Gould, 2009). Lead poisoning has also been linked with behaviors disorders that result in delinquent and violent behavior. Gould (2009) found the total direct costs linked to lead crime costs would be \$1.8 billion dollars including victim costs, legal proceedings, incarceration and lost earnings of the victim and criminal. An additional \$ 11.6 billion dollars is lost through indirect costs in psychological and physical damages, medical costs, and preventative measures because of criminal action (Gould, 2009).

Research is thus needed to assist in identifying the decision-making processes of caregivers to remain engaged in LFS programs and the social and contextual processes that also impact on this decision-making process. The development of a beginning substantive theory may assist nurse and health providers to facilitate family's increased engagement in LFS programs and ultimately also address Healthy People 2020 objective to eliminate elevated BLL in US's children (Healthy People 2020, 2012).

Definition of Terms

Terms defined for this study are as follows:

Caregivers. Caregivers in this study are defined as individuals who are looking after a child or children with a BLL that is greater than 10µg/dL and require LFS at least twice after the initial screening for lead.

Health decision making. Health decision making is the process that might include whether to seek health care, take prescribed medications, what to eat, exercise, engage in an intervention, etc.... These decisions are carried out daily and are not made only derived from

biomedical criteria but are influenced by the external environment, personal preferences, and availability of choices or access. Health decisions are shaped by a wide range of contextual factors such as social, economic, political geographical and institutional conditions (Charise et al., 2010).

Social Contexts and Process. Social contexts and processes for this research are defined using Social Context Theory. The Social Context Theory is a model that identifies Social Environment which has three major components; 1) Societal structures (shapers), 2) Social Processes (perceptions, attitudes, values), and 3) Common Patterns of Social Behavior (social realities). Social Structures or shapers are macro social forces that impact on the way that individuals approach daily living and relationships. These impacts are external to the individual such as social class, technology, demography, urbanization, mass media and social institutions. These institutions influence the pattern of social behavior among and between people at the family level, in education, religion, leisure, health, economy, work, and government activities of daily living (Earle & Earle, 1999).

Social processes include internal forces such as an individual's perceptions, attitudes, and values and these forces are pivotal to the socialization of persons in society. Social processes serve as social supporters, as they provide consistency and uniformity in people's view, and can be a facilitating and non-facilitating link between societal structures and commonly accepted social behavior patterns (Earle & Earle, 1999). Common patterns of social behavior represent the social realities that guide most individual's thinking and actions. This is a collective acknowledgement and incorporates folkways, mores/norms and laws in society (Earle & Earle, 1999)

Engagement. Lead follow-up screening programs are considered part of the treatment process of lead poisoning, so the definition of engagement included the key word, treatment.

Treatment engagement for this study was developed using the components outlined by Karver, Handelsman, Field, and Bickman, (2005); Staudt, (2007) with caregivers of at risk children for mental health services and the recommendations by ACCLP Prevention (2000). One component of engagement is the behavioral performances necessary by caregivers to implement treatment and achieve outcomes. These factors include appointment keeping, completing modification of home environment, discussing barriers of being able to attend appointments, modifying the home environment, accessing and enrolling in all recommended adjunct resources i.e. medical nutritional therapy (MNT). Other areas include expressing any concerns surrounding the child's health and responding to requests of the practitioners. The second component to treatment engagement is attitudinal. It is the belief that treatment is beneficial, and the result is an emotional commitment and investment in the treatment process. "Clients who are emotionally invested in treatment have a positive attitude toward treatment and perceive it as an endeavor that is worth their time and energy" (Staudt, 2007, p. 185).

Elevated Lead Level (ELL). An elevated lead level for children under 72 months of age is any lead level that is equal to or greater than 10µg/dL (KYCLPP, 2010).

Lead Burden. Lead burden is a common finding in humans with 90 to 95% of total adult lead body burden stored in the bones (Barry, 1975). Blood lead levels reflect current exposure either from external lead sources or bioavailable internal sources. There are differences in toxicokinetic handling of lead from person to person and as a result the blood half-life has been estimated to be approximately 30 days. Bone half-life has been found to be 27 years with the differences between stable cortical bone (inert lead pool) and trabecular bone (more bioavailable

lead storage (Agency for Toxic Substances and Disease Registry [ATSDR], 2007). Lead impacts on multiple organ systems including the nervous, hemopoietic, renal, endocrine, and skeletal systems. Lead poisoning occurs slowly and with the gradual accumulation of lead in tissues and bone over time and repeated exposures result in permanent damage to internal organs. Lead poisoning in children is especially significant as this damage occurs during critical developmental periods (Gemmel et al., 2002; Hegde, Sridhar, Rao Bolar, Arehalli Bhaskar, & Bharat Sanghavi, 2010; Needleman & Gatsonis, 1990).

Lead Follow-up Screening. The process for LFU screening is implemented as outlined by the Kentucky Cabinet for Health and Family Services (2012) and in accordance with the child's BLL as shown in Table 1.

Level of concern or lead poisoning or lead poisoning is noted in a child with a BLL greater than 10 µg/dL. Blood lead level of 15-19 µg/dL is considered moderate and at the level of 20-44 µg/dL is considered high. Levels that are 45 or higher are considered very high (Koplan, Richard, McGeehin, & Noonan, 2002).

Administrative Lost to Follow-up. Administrative lost to follow-up for this study is considered when three attempts to contact a caregiver, one being registered letter, a home visit attempt or three appointments made and not kept occur (Kentucky Cabinet for Family and Child Services [CHFS], 2006). Case managers, in unique cases, may necessitate additional attention such as contacting any known contacts, including the primary care provider to alert them of the child's ELL. Additional referrals to social services or complimentary programs may be recommended depending on the circumstances (KYCLPP, 2010).

Summary

Lead exposure is one of the most significant environmental child health and developmental issue in the US. Even low levels of lead exposure have resulted in significant childhood cognitive impairment and behavioral issues (Mendelsohn et al., 1999; Canfield et al., 2003). Thus, it is imperative that children with ELL and their caregivers remained engaged in LFS programs. Kentucky Program Director, case managers and clinic nurses have identified ‘lost to follow-up’ or failing to remain engaged in LFS as an issue. Studies following lead level screening and timing for declines of lead levels have also identified significant attrition rates in LFS and LFU. In the Northern Kentucky District WIC services are also offered in the Health Department resulting in children who are LFU and are not receiving this very important nutritional service.

Chapter Two: Literature Review

Grounded theory is a method of scientific inquiry that allows for the uncovering of social process, actions, and contexts that impact on the decision of caregivers to remain engaged in LFS programs (Glaser & Strauss, 1967). It is essential to understand this process so that lead program directors, case managers and lead nurses can best provide support and develop programs to ensure the continuation of caregiver's engagement the LFS process. In grounded theory a review of literature is a tool, a beginning point, which exposes the researcher and assists sensitization of concepts, guiding interest, and providing a disciplinary perspective of the phenomenon under consideration. The exposure to these concepts also helps with the development of ideas, formulation of questions to be asked, and guides the concern of the study while allowing the consideration of these concepts through multiple levels of analysis (Charmaz, 2006). Exposure to these concepts increases the knowledge of the researcher about issues that surround the phenomenon instead of the researcher making assumptions before and during the analysis (Glaser, 1978; Charmaz, 2006).

Lead Poisoning

The history of lead poisoning.

Lead is a soft naturally occurring metal which is used in materials and products in manufacturing, burning of fossil fuels, and mining (Cohen, 2001). Lead poisoning was first identified in ancient times in 200 BC. The Greek physician Dioscordies observed that "lead makes the mind give way" (Koller, Brown, Spurgeon, & Levy, 2004, p. 987). Lead was added to paint as far back as 1884 because it made paint more durable and adhesive. In 1921 General Motors developed tetraethyl lead and added it to gasoline to decrease the amount of engine knock. Gasoline exhaust was considered the largest source of lead until it was phased out in

1970's. Today roadways and the soil areas around them remain highly contaminated with lead (Askari & McDiarmid Jr., 2003). The lead industry from the 1920s through the 1950's touted lead in it's' advertisements as "Lead... is contributing to the health, comfort, and convenience of people today as it did when Rome was a center of civilization" (Askari & McDiarmid Jr., 2003, p. 2). Lead poisoning was identified in the 1960's as a serious health threat in the United States. Banning the use of lead in paint in 1978 and in gasoline in 1986 has improved the health of Americans immensely (Askari & McDiarmid Jr., 2003).

In 1971 The Lead Based Poisoning Prevention Act was passed which began the movement to reduce the amount of lead that was put into paint, gasoline, food cans, plumbing and house hold products. Lead poisoning has been reduced from 88.2% in 1976 to 4.4% in 1994. Although extremely high levels of lead poisoning are rare low levels continue to be a problem today (Cohen, 2001).

In 1992 the Act: Section 1018 of the Residential Lead-Based Paint Hazards Reduction Act of 1992 (Title X of the Housing and Community Development Act of 1992) was passed that requires sellers, landlords, and real estate agents to warn potential buyers and tenants that the property dating pre-1978 may contain lead-based paint and lead-based paint hazards (Residential Lead-Based Paint Hazard Reduction Act Rules and Regulations, 1992).

In April 2008 the Environmental Protection Agency (EPA) issued the Renovation, Repair and Painting Rule. This requires that all firms performing renovation, repair, and painting projects on pre-1978 homes, child care facilities and schools be certified as lead safe by the EPA. All renovations are required to be completed by certified renovators who are trained by EPA in lead-safe work practices. These lead safe work practices include containing the work area, so

dust is collected and not spread, minimizing the amount of dust created and thoroughly cleaning up the area (EPA, 2012).

Childhood lead poisoning

Elevated blood lead level is defined as “any blood level $\geq 10 \mu\text{g/dL}$ ” (Koplan, Richard, McGeehin, & Noonan, 2002, xix). The new CDC guidelines recommend that there be no level of concern as there really is not a safe level of lead in the blood and a level of $5 \mu\text{g/dL}$ requires case management and follow-up (CDC, 2012). Lead affects almost every system of the body and is ingested most commonly through swallowing. Lead impacts mostly children under the ages of six as it is easily absorbed into their bodies and interferes with the normal growth and development of their brains and organs. Children under the age of two are at the highest risk for the effects of lead (Alliance to End Childhood Lead Poisoning [AECLPP], 1999). Children readily absorb up to 50% of the lead they are exposed to, as contrasted to adults that only absorb 10%. A single paint chip the size of a dime can have 50-200 mg of lead in it. Three of these paint chips ingested by a child daily would equal 1,000 times the amount allowed for an adult daily (Cohen, 2001). High levels of lead exposure can cause mental retardation, coma, convulsion and death; however, this is very rare. Children are more likely to have chronic low-level exposure that results in reduced I.Q, shortened attention span, hyperactivity, learning disabilities, and other health problems (AECLPP 1999).

A study completed by Lanphear et al, (2000) demonstrated that even the lowest BLL concentrations were associated with deficits in cognitive functioning and poor academic achievement. The authors used data from the National Health and Nutrition Examination Survey, (NHANES III) that was done from 1988 to 1994. They assessed the relationship between BLL and the results on Wide Ranging Achievement test arithmetic and reading scores

(WRAT) and the Wechsler Intelligence Scale for Children-Third Edition, (WISC-III). A total of 4,853 children between the ages of 6 to 16 years of age were tested. The children had a mean BLL of 1.9 $\mu\text{g}/\text{dL}$, 172 of the children had BLL greater than 10 $\mu\text{g}/\text{dL}$. The results indicated an inverse relationship between BLL and scores on the cognitive tests.

For every 1 microg/dl increase in blood lead concentration, there was a 0.7-point decrement in mean arithmetic scores, an approximately 1- point decrement in mean reading scores, a 0.1-point decrement in mean scores on a measure of nonverbal reasoning, and a 0.5-point decrement in mean scores on a measure of short-term memory” (Lanphear, Dietrich, Auinger, & Cox, 2000). An inverse relationship was also seen for BLL that were below 5.0 microg/dL and arithmetic and reading scores (Lanphear et al., 2000).

Another study completed by Lanphear, Dietrich, and Berger (2003) indicated that there is not a discernible threshold for cognitive deficits because of lead exposure. Because of this finding this group of authors stresses the importance of primary prevention and reducing children’s exposure from residential lead hazards.

Canfield et al., (2003) measured the BLL of 172 children at 6, 12, 18, 24, 36, 48, and 60 months and had the Stanford-Binet Intelligence Scale at the age of three and five years of age. The results of this study indicated that the effect of blood lead concentration was inversely and significantly related to IQ. In the linear model an increase in 10 $\mu\text{g}/\text{dL}$ had a 4.6 decrease in IQ ($p=.0004$). This study also found that blood lead had a greater effect proportionally on I.Q at lower levels of lead concentrations.

The semi parametric analysis indicates a loss of 7.4 IQ points for a lifetime average blood lead concentration of up to 10 $\mu\text{g}/\text{deciliter}$. These findings suggest that the total lead-

related impairment in this cohort is due largely to the initial I.Q. loss at blood lead concentrations of 10 µg per deciliter or less and that the linear model for children with peak concentrations of less than 10 µg per deciliter overestimates the lead-associated impairment (Canfield et al., 2003, p. 1524).

Cecil, Lenkinski, and Villegas (2001) described many investigators questioning the association of exposure and decreased intellectual and cognitive functioning related to lead poisoning. The contention of other investigators as reported by Cecil, Lenkinski, and Villegas, (2001) is that other variables such as social class, family size, maternal education, quality care, marital relationship in home, prenatal and postnatal stressors, and iron deficiency have a negative impact on cognitive functioning. To determine the effects of lead exposure, Cecil, Lenkinski and Villegas (2001) investigated the effects of lead on the cortical gray matter of the brain using magnetic resonance spectroscopy, (MRS) to determine if there were any neurotoxic effects on the nervous system. By monitoring the brain's neurochemicals with MRS the investigators were able to measure the number of neurochemicals in the brain. The lead exposed individuals had a normal magnetic resonance imaging (MRI) scan however; they showed significant reduction in the levels of N-acetylaspartate/creatine and phosphocreatine ratios in the frontal gray matter. Diminished levels of these neurochemicals indicate a reduced level of neuronal viability, which was found to be significantly reduced in gray matter compared to the control group that had not been exposed to lead in an unpaired t test($p=.0345$). Both subjects and control individuals came from the same socio-economic backgrounds and home environments. The only major difference between the groups was the elevated lead levels. The findings of this study suggest that lead exposure does have some effect on cognitive and intellectual functioning (Cecil, Lenkinski, & Villegas, 2001).

Studies have suggested that children exposed to lead in their early lives are at higher risk for behavioral problems, learning difficulties and once they are adults are more likely to display antisocial, violent, and criminal behavior. Chen, Cai, Dietrich, Radcliffe, & Rogan, (2007) performed a secondary analysis using the data from a clinical drug trial administering the drug succimer, which is a chelating agent for high levels of lead poisoning. The children during this trial had ELL that ranged between 20-44 $\mu\text{g/dL}$ and were between the ages 12 to 33 months. The children ($n=780$) were followed between ages 2 to 7 year of age. The scores on the Conners' Parent rating scales-Revised scores at 5 years and Behavioral Assessment Systems for Children (BASC) at 7 years were not associated with BLL at 2 years of age. At 7 years of age the BLL had a direct impact on the BASC systems index, externalizing, and for school problems. This study found that high concurrent BLLs had both a direct and indirect impact on school age children. Another study had school teacher's assessments of their students ($n=756$), aged 3-7 years, using Conner's Teacher Rating Scals-39, Conner's ADHD/Diagnostic and Statistical Manual for Mental Disorders, 4th Edition Scales(CADS) and Behavior Rating Inventory of Executive Function questionnaires, and BLLs using a Lead Care Machine. Mean BLL was $11.4 \pm 5.3 \mu\text{g/dL}$ and BLL were associated with higher anxiety ($\beta=.27$; $p=0.01$), social problems ($\beta=.20$; $p=0.01$), and higher ADHD scores ($\beta=.17$; $p=0.05$), global executive functioning ($\beta=.42$, $p=0.001$) (Roy et al., 2009).

Wright et al. (2008) sampled 250 participants who were between the ages of 19 and 24 years of age and had previously taken part in the Cincinnati Lead Study and had BLL's sampled during the prenatal period, early childhood and at 6.5 years of age. Blood lead samples from prenatal and early childhood periods were significantly linked to high rates of criminal arrests during young adult hood. Adjusted total arrests rates were greater for each $5\mu\text{g/dL}$ ($0.24\mu\text{mol/l}$)

increase in BLL, RR=1.40(95% confidence interval [CI] 1.07-1.85) for prenatal BLL, 1.07(95% CI 0.88-1.29) for average childhood BLL, 1.27(95% CI 1.03-1.29) for 6-year-old BLL. Adjusted arrest rates for violent crimes were greater for each 5µg/dL increase in BLL, RR= 1.34 (95% CI 0.88-2.03) for prenatal BLL, 1.30 (95% CI 1.03-1.64) for average childhood BLL, and 1.48 (95% CI 1.15-1.89) for 6-year BLL.

The impact of lead is also strongly associated with the increase incidence of dental caries in school-age children. In a group of children, ages 6-10 years of age (n=543) being enrolled in the Children's Amalgam Trial to assess the impact of mercury in fillings, BLL's were positively associated with number of caries. In urban children, even with adjustments made for demographics, maternal factors, and dental practices, the mean number of tooth surfaces with carious lesions was significant in urban subgroups versus rural (p=0.002), and for both primary teeth (p=0.047) and permanent teeth (p=0.047). The BLLs were low with a mean of 2.3 µg/dL (SD1.7) and was higher in the urban group versus rural (p>0.0001) (Gemmell et al., 2002).

Cross sectional studies in the third National Health and Nutrition Examination Survey (NHANES) analyzed the relationship between BLL and pubertal development in females between the ages of 8-18 (n=2186) that were broken out into self-reported ethnic groups: n=600 non-Hispanic white, n=805 non-Hispanic African American and n=781 Mexican –American girls. Puberty was measured by the age of menarche and Tanner stage for pubic hair and breast development. The geometric BLL mean was less than 3µg/dL (0.144µmol per liter) in all three groups. Lead concentrations of 3µg/dL as compared to 1µg/dL and were associated with decreased height (p<0.001), after adjustment for age, race and other factors. Significant delays in breast and pubic hair development were found with 3µg/dL lead concentrations in African American and Mexican American groups. African American girls' delays were most significant

in reaching Tanner stages 2, 3, 4, and 5 with BLL $3\mu\text{g/dL}$ as compared to $1\mu\text{g/dL}$ with breast development 3.8, 5.3, 5.8 and 2.1 months respectively and 4.0, 5.5, 6.0 and 2.2 months for pubic hair development. The delay in menarche was 3.6 months. White girls experience non-significant delays in all pubertal measurements with BLL of $3\mu\text{g/dL}$ (Selevan et al., 2003).

Childhood lead poisoning in the United States, and the state of Kentucky.

In 2006 there were 27.9 million children in the US less than 6 years of age (US Census Bureau, 2008 as cited in Gould, 2009). Of these children 24.7% had BLL between 2-10 $\mu\text{g/dL}$ or 6.9 million. Children who are more likely to have higher than average BLL are likely to be male, Hispanics, African Americans and children in household below 200% the poverty line (Gould, 2009).

Children's BLL continue to decline in the US even in high risk groups. Data from the NHANES Phase I, 1988-1991, Phase II, 1991-1994, were compared to Phase III, 1999-2004. Elevated lead levels $\geq 10\mu\text{g/dL}$ declined from 8.6% in 1988-1991 to 1.4% in 1999-2004. Levels continue to remain high in non-Hispanic black (5.2-2.8 $\mu\text{g/dL}$), compared to Mexican American (3.9-1.9 $\mu\text{g/dL}$), and non-Hispanic white children (3.1-1.7 $\mu\text{g/dL}$). Levels across the US continue to be higher in non-Hispanic Black children compared to Mexican American and non-Hispanic white children. The distribution of BLL are: 14.0% were $<1.0\mu\text{g/dL}$, 55% were 1.0 to 2.5 $\mu\text{g/dL}$, 23.6% were 2.5 to $<5.0\mu\text{g/dL}$, 4.5% were 5.0 to $<7.5\mu\text{g/dL}$, 1.5% were 7.5 to $<10\mu\text{g/dL}$, and 1.4% were $\geq 10\mu\text{g/dL}$. A multivariate analysis demonstrated that major risk factors for ELL were residence in older housing, poverty, age and being non-Hispanic (Jones et al., 2009). However, with the evidence that poor health outcomes are experienced with BLL $<10\mu\text{g/dL}$ and another study establishing risks to health at BLLs $\geq 5\mu\text{g/dL}$, the percentage of children who are being impacted by lead's risks is that much greater (Bernard & McGeehin,

2003; Canfield et al., 2003; Lanphear, Dietrich, Auinger, & Cox, 2000; Lanphear et al., 2005).

The same study that found health risks even with BLLs ≥ 5 $\mu\text{g/dL}$, also found that the children with BLLs between 5-9 $\mu\text{g/dL}$ had lead exposure from multiple sources. Due to the lower BLLs these children did not have the obvious risk factors that are ordinarily found in children with higher BLLs (Bernard & McGeehin, 2003). Jones et al., (2009) also found that most children in the U.S. have some exposure to lead and have low-level BLLs and because there is not a 'safe' lead level this is concerning.

There are significant disparities in children who have ELL and these children are considered high risk groups. Children who live in urban areas and are poor have a higher body lead burden. Children who live in poverty, receive Medicaid benefits, and live in lower value housing districts have higher lead levels than children who do not (CDC, 2005).

Landrigan, Rauh, & Galvez, 2010 indicate that:

Lead poisoning is disproportionately concentrated in poor minority communities in the United States This reflects the fact that older (pre-1978) housing units that are in poor repair are disproportionately concentrated in these neighborhoods. The resulting environmental injustice is documented in the sharp disparities observed in the distribution of elevated blood lead levels in American children by race and income (p. 183).

In the State of Kentucky 57% of the housing stock was built on or before 1979 which increases the risk for housing health hazards such as structural deficiencies, poor ventilation and hazardous agents such as dust mites, pests, and molds (US Census Bureau, 2010; Clouse, 2010). The poverty rate in Kentucky is 17.4% which is higher than the national average of 14% and 27.4% of children under the age of five years live below the poverty line (US Census Bureau 2006-2008 as cited in Clouse, 2010). In the state 45.2% of the children are enrolled in Medicaid

benefits. All these factors are used to determine the lead hazard risk for children in the state (Kentucky Medicaid Services in 2009 as cited in Clouse, 2010).

The highest risks for lead poisoning in the State of Kentucky are found in the urban areas of Louisville/Jefferson County, the Northern Kentucky District (NKY), and Lexington. These areas have higher concentrations of housing built before 1950, high number of poorly maintained homes, large numbers of children receiving Medicaid benefits, large minority populations, and large number of children overall. Each of these counties and regions receive CDC pass through funds for risk assessment, case management services, prevention and outreach services for high risk children for lead poisoning as shown in Figure 1 (Clouse, 2010). Northern Kentucky does not receive Healthy Homes funding to assist with the modification of the housing stock (S Lawson, personal communication, April 16th, 2012).

The prevalence rate of ELL (level greater than 10 µg/dL in Kentucky's children under the age of 36 and 72 months since 2000 has decreased by 83% (see Figure 2). In the NKY district the rates of BLL \geq 10 µg/dL for children 72 months or younger in the years 2005-2009, in two highest counties of risk in this region, range from 33.6-54.8 per 1000 children to 71.9-120 per 1000 children. In Campbell County the prevalence rate is 71.88% (Clouse, 2010) (see Figure 3).

Cost of Lead Poisoning

Review of literature for the most current cost estimates on addressing housing, cost of treatment, IQ and earning potential, special education, and behavior and crime, was carried out. Many of the newest articles published had estimates that were developed using previously published costs and inflating these costs to reflect Consumer Price Index (CPI) for the year the work was completed.

Cost of addressing housing. In 2003, Smith Korfmacher, 2003 estimated that the average cost of making housing lead safe is between \$1,000 and \$ 40,000 per housing unit, the national average is approximately \$ 7,000 per unit. Gould, (2009) using the Presidential task force lower and upper bound ranges reviewed this 2003 estimate and project that the costs in 2006 United States dollars (USD) to be between \$1,200 to \$10,800 per unit which were in line with Smith Korfmacher's finding. The US Department of Housing and Urban Development (2002) estimated there are 38 million homes with lead hazards, 24 million of these homes considered to have significant lead hazards. Four million of these homes have children under the age of six residing in them in 2006. By Gould's (2009) estimation 1.02 million of these homes are significant for lead hazards. To target these homes would cost between \$1.2 to \$10.2 billion USD.

Cost of treatment. Trasande and Liu, (2011) estimated medical costs for lead poisoning were \$ 5.9 million and an additional "\$ 50.9 billion (sensitivity analysis: \$44.8-\$60.6 billion) in lost economic productivity resulting from reduced cognitive potential from preventable childhood exposure" (p. 865). Treatment for children who have an ELL at lower levels require repeated monitoring of BLLs and prevention of further exposure and at higher BLLs chelation is required. Kemper (1998) first estimated the costs of treatment and these estimated costs were inflated by Gould (2009) to reflect 2006 USD Consumer Price Index. Screening and treatment costs are as follows: venipuncture (\$8.57), capillary blood sampling (\$4.29), lead assay (\$23), risk assessment questionnaire (\$2), nurse-only visit (\$42), physician visit (\$105), environmental investigation and hazard removal (\$440), oral chelation (\$332), and intravenous chelation (\$2,418). Children with BLLs between 10 to 20 µg/dL require further testing and nurse visits for a total cost per child of (\$74). With BLLs between 20 to 45 µg/dL the CDC recommends 8 visits

for testing and nurse follow-up and environmental investigation of the home at (\$1027) per visit per child. Blood lead levels between 45 to 70 $\mu\text{g/dL}$ includes all the visits listed previously and oral chelation at a cost (\$1,335) per child. Levels greater than 70 $\mu\text{g/dL}$ require intravenous chelation with a cost of (\$3,444) per child.

An analysis to determine the economic cost of lead poisoning small sample sizes were an issue for subgroups for each level of BLL so a ratio of CDC confirmed cases at the state level and the number of cases found in the NHANES were used and applied to each subgroup. Across all groups the cost of direct lead treatment, not considering the lifelong health effects, is between \$10.8 and 53.1 million as shown in Table 2 (Kemper, Bordley, & Downs, 1998; Gould, 2009). Much of health care costs for lead poisoning are paid through Medicaid since the largest portion of children poisoned are the recipients of Medicaid benefits. Research also shows that there are additional diseases that are the effects of lead poisoning that have not been included in the cost of health care (Smith Korfmacher, 2003). (See Table 2).

IQ and lost earning potential. There is a strong correlation between ELL and lowered I.Q and research indicates that a lowered I.Q. results in reduced income over an individual's lifetime. Gould, drawing off estimates already completed indicated that for each IQ point lost a reduction in life time earnings of \$17, 815 (in 2006 USD) (Salever, 1995; Schwartz, 1994; Nevin et al., 2008 as cited in Gould, 2009). For all children in the 2006 cohort \leq age of 6 years the net lifetime earning loss would fall between \$164 and \$233 billion. This estimate includes lower education achievement, workforce participation, and a lower hourly work wage. With lower lifetime earnings also comes lower tax revenue for government. Smith Korfmacher (2003) using Grosse et al. methodology estimated that the state of New York is losing \$78 million per year.

The same application with a 15% marginal tax translates to lost tax revenue of \$25 to \$35 billion for each cohort of lead poisoned children as shown in table 3 (Gould, 2009).

Special education. Medical research also has strongly linked lead poisoning and impaired neurobehavioral function. Lead poisoning has been associated with not only lower I.Q but lower-class standings in high school, increased absenteeism, lower vocabulary and grammatical-reasoning scores, poorer hand-eye coordination, longer reaction times and slower finger tapping (Needleman et al. as cited in Smith Korfmacher, 2003). These results certainly would support the need for special education. Studies have shown that 20% of children with BLLs over 25 ug/dL have required special education for at least 3 years and need assistance from experts such as reading teachers, psychologists and/or other specialists (Schwartz as cited in Smith Korfmacher, 2003). Reducing lead in the environment could potentially save \$ 14,317 per child (inflated to 2006 USD) in special education costs (Smith Korfmacher, 2003; Gould 2009). Using Schwartz (1994) estimation of the percentage of children requiring special education and using the same bound analysis the average cost per child for 3 years of special education are estimated to be \$30-\$146 million for each cohort of lead poisoned children (Gould, 2009).

Attention deficit hyperactivity disorder (ADHD) is a lifetime psychiatric disorder that puts children at higher risk for conduct disorders, antisocial behavior, criminal behavior and drug abuse and has also been linked to early lead exposure. (Costello, Mustillo, Erkanili, Keeler, & Angold, 2003). Treating this disease requires a combination of prescription drug therapy and counseling. (Braun, Froehlich, Auinger, & Lanphear, 2006) estimated that of the 1.8 million children between the ages of 4 to 15 years of age with ADHD, 21.1% are linked to have had BLLs greater than 2µg/dL. The costs of treatment for drug therapy and counseling are \$565 per child and work loss for parents \$119 per child. This equates to a \$267 million annual cost to

families and society and this estimate is considered a conservative lower bound estimate (Gould, 2009).

Behavior and crime. Research has shown that lead poisoning may contribute delinquent and violent behavior because of neurobehavioral dysfunction. Nevin (2000) found the 90% variation in violent crime rates from 1960 to 1998 is explained by childhood lead gasoline exposure from 1941 to 1986. The use of lead paint explains the variation of 70% in the murder rates from 1900 to 1960. Reyes attributes the introduction of the Clean Air Act (EPA, 2009) in 1970's and 1980's for crime dropping by one- third in the 1990s (as cited in Gould, 2009). Nevin (2006) estimated of the annual number of crimes that would be averted with a 1 µg/dL reduction in preschool BLLs was used to estimate the fewer burglaries, robberies, aggravated assaults, rapes, and murders as shown in table 4. The total direct costs linked to fewer lead linked crime costs would be approximately \$ 1.8 billion including victim costs, legal proceedings, incarceration and lost earnings of victim and criminal (Gould, 2009). This estimation is small compared to the number of children would have had lead exposure that in turn increases the risk-taking behaviors of an individual and results in crimes, accidents, etc.... Overall an additional \$ 11.6 billion dollars is lost through indirect costs in psychological and physical damages, medical costs, and preventative measures because of criminal action (Gould, 2009). Lane et al., (2008) also found that children with BLL > 20µg/dL were at increased likelihood to engage in risk taking behaviors. The study found that moderate ELLs were strongly linked to teenage pregnancies and smoking in low income youth which again has sizeable costs to communities and society.

Each state subsidizes CLPPP that are responsible to educate, prevent, and respond to cases of lead poisoning. The screening structure of this program would have to remain but

addressing lead hazards would certainly be reduced if not totally eliminate the need for the CLPPP. The cost savings realized for eliminating the role the CLPPP is hard to estimate as funding and the roles these programs differ from state to state. For the state of New York in 1999 the annual average cost of environmental investigations was \$959,105 and the estimated cost per year from the Department of Health for supplemental lead poisoning prevention grants was \$8 million per year (Smith Korfmacher, 2003).

The benefit of lead hazard control ranges from \$181 to \$269 billion which would realize a return of \$ 17-\$221 for every dollar invested as shown in table 5. This is a very conservative estimate and does not account for the savings in health care later in life, neonatal mortality, lead control on property values, energy savings, community improvement, lead paint litigation, indirect costs of criminal activity, and other benefits (Gould, 2009).

Potential Sources for Exposure of Lead and Control

Housing has been identified as one of the largest sources of lead in the environment. Lead based paint was used in homes prior to 1978 until it was phased out. Lead base paint is defined as “paint or other surface coating that contains lead equal to or exceeding 1.0 milligrams per square centimeter or 0.5% by weight or 5,000 parts per million by weight” (ACLPPP, 2004, p. 15). As the paint deteriorates the lead is released into the home environment in the form of dust. The recommendation for the prevention of childhood lead poisoning is the control of exposure to lead-based paint hazards in housing. Lead hazard is defined as “accessible paint, dust, soil or other sources or pathway that contain lead or lead compounds that can contribute to or cause elevated BLLs” (ACLPPP, 2004, p. 15). Approximately 40% of all American housing has lead based paint and 25% contain significant lead hazards (ACLPPP, 2004). A lead hazard screen is “a limited environmental screening activity focused on visual assessment, which may

include paint, dust and soil sampling and is usually performed in housing units less likely to contain lead-based paint hazards or as a preliminary step in the lead hazard assessment process” (ACLPPP, 2004, p.15). A lead risk assessment is “an onsite investigation of a residential dwelling to discover any lead-based paint hazards and descriptions of options to eliminate them, which includes lead dust and soil sampling” (ACLPPP, 2004, p. 15).

The CDC guidelines indicates that an assessment of environmental lead hazards needs to be completed when a child has a lead level that is greater than 15 µg/dL. This includes: 1) inspecting the child’s home or sites where he or she spends more than 6 hours per week; 2) documenting the history of exposure; and 3) measuring environmental lead levels of house dust, paint that is not intact, exposed soil, other sources as necessary (Koplan et al., 2002). The lead dust hazard standards have been set for 40 micrograms per square foot (µg/ft²) for floors and 250µg/ft²) for interior windows sills. The standards for soil lead hazards has been set at 400 parts per million, (ppm) in play areas of bare residential soil and 1,200 ppm for the rest of the yard (EPA, 1999).

Interim controls are “a set of measures designed to temporarily reduce human exposure to lead based paint hazards” (Advisory Committee on Childhood Lead Poisoning Prevention [ACLPP], 2004, p. 15). Essential maintenance practices are “approved maintenance practices and procedures designed to control deteriorating paint and/or lead dust that are undertaken regularly to ensure a home is maintained in a lead-safe condition. These practices involve dust and paint chip containment using “wet” procedures and specialized cleanup” (ACLPP, 2004, p. 14). Clearance examination is the “visual examination and collection of lead dust samples by an inspector or risk assessor and analysis by an accredited laboratory upon completion of an

abatement project, interim control intervention, or maintenance job that disturbs lead-based paint (or paint suspected of being lead-based) above the minimums levels” (ACLPP, 2004, p.14).

Lead abatement is a “procedure that eliminates lead-based paint hazards or lead-based paint. The four types of abatement methods are removal, enclosure, encapsulation, and replacement” ((Environmental Protection Agency [EPA], 1999, p. 65). The EPA requires that a certified abatement contractor be used. If lead abatement is done incorrectly it puts the child at greater risk for lead poisoning. Lead abatement contractors can take steps to ensure that the home is protected so that lead dust is unable to accumulate. If done correctly lead abatement should significantly reduce lead hazards in the home (EPA, 1999).

Lead exposure can also occur from soil around the home when children play in yards and ingest or inhale lead dust or lead contaminated soil. Drinking water from older lead plumbing or lead solder can also be a source of lead contamination. Certain occupational jobs, held by caregivers, can also introduce lead into a child’s environment by transporting lead on hands and clothes from the work site. Less common sources of exposure are older painted furniture and toys, food and liquids stored in lead crystal or lead-glazed pottery or porcelain, and lead smelters or other industries that release lead into the air. Hobbies that use lead such as; making pottery, stained glass, fishing sinkers, and refinishing furniture are another source, as well as, folk remedies that contain lead such as ‘greta’ and ‘azarcon’ that are used to treat an upset stomach (EPA, 2012).

Lead Poisoned Children and Their Caregivers

There are significant health disparities for children who have EBL and these children are considered high risk groups. Children who live in urban areas and are poor have a higher body

lead burden. Children who live in poverty, receive Medicaid benefits, and live in lower value housing districts have higher lead levels than children who do not (CDC, 2005).

Children who immigrate to the US from other countries (i.e. Asia, Africa or Eastern Europe) should also be screened for lead poisoning. Many of these children have lived in impoverished households with dilapidated housing, where little or limited industrial or environmental controls are in place and the use of leaded gasoline is still very prevalent (Woolf et al., 2007). Landrigan, Rauh, & Galvez, 2010 indicate that:

Lead poisoning is a disproportionately concentrated in poor minority communities in the United States This reflects the fact that older (pre-1978) housing units that are in poor repair are disproportionately concentrated in these neighborhoods. The resulting environmental injustice is documented in the sharp disparities observed in the distribution of elevated blood lead levels in American children by race and income (p. 183).

Families who live in the highly leaded environments are poor, minorities, marginalized, and oppressed, whose voices are not heard. The dominant culture whose members assist these families has denied the evidence of lead toxicity to communities (Lanphear, 2007).

Lanphear (2007) elaborates on the social and political issues that have aided in the continuation of lead as an environmental problem:

Swayed by industry's expertly packaged arguments, public health officials and pediatricians found it convenient to blame the consequences of lead toxicity on poverty, poor parenting or pica. Meanwhile, epidemiologists fretted about unmeasured confounders and the limitations of observational studies. In our quest for scientific certainty, we inadvertently delayed the promulgation of regulations at the expense of public health (p. 484).

Regulations that were enacted over the past three decades have dramatically improved the health outcomes of children and exposure to lead yet despite this evidence this country continues to rely on secondary prevention strategies (Lanphear, 2007).

Lead poisoned children are a vulnerable population as they are dependent on others for their wellbeing such as parents or caregivers. Environmental toxins have a much greater impact on children because of physiological and developmental factors. Caregivers and families of lead poisoned children are also a vulnerable group. Race, income, housing options account for the differential distribution of environmental health in communities (Ryan, 2006).

Appalachian Health and Well Being in the Greater Cincinnati Region

Due to the large migrations in the 20th Century of the Appalachian people there are significant numbers of migrants living outside the federally designated Appalachian regions. Despite the passage of time Appalachian migrants and their descendants still experience the same socioeconomic and health concerns their cohorts do who are still residing in Appalachia regions (Obermiller, 2004; Obermiller & Howe, 2007). The Greater Cincinnati Community Health Status Survey reported that 47% of the Greater Cincinnati population have Appalachian heritage. This heritage was determined by the identifier type of first generation Appalachian based on state and county of birth, first or second generation based on county and state of parent's birth, others self-identified as Appalachian, while others had family roots in Appalachian regions. Urban Appalachian people are essentially an 'invisible minority' with 10.7% first generation, 24.5%, first and second generation, 16.0% self-identified, 32.3% with family roots. A total of 61% indicate they live in the suburbs of Cincinnati which also encompasses the Northern Kentucky region. Individuals with Appalachian heritage residing in the Greater

Cincinnati region are considered Urban Appalachians (Ludke, Obermiller, Rademacher, & Turner, 2012).

Appalachian adults. The first-generation Appalachian adult in the Greater Cincinnati region has poorer oral health and quality of life than white non-Appalachian adults and this has not changed since 1999 (Ludke, Obermiller, & Horner, 2012). Depression is an increasing problem for this population and they may also be at greater risk for chronic physical diseases than white non-Appalachian adults. Over time this group has had increasing prevalence for high blood pressure, high cholesterol and/or triglycerides levels. First generation white Appalachians are more likely to live in less urban environments and have a lower socioeconomic status than white non-Appalachian. White Appalachians are more likely to use tobacco, be overweight, be physically inactive, and consume a diet that contributes to poor health (Ludke et al., 2012).

Appalachian children. First and second generation white Appalachian children residing in the Greater Cincinnati region are comparable in health status and health utilization as white non-Appalachian children (Ludke et al., 2012). Appalachian children may be at greater risk for poor behavioral and emotional health issues potentially increasing over time than white non-Appalachian children. Appalachian caregivers participating in survey may have different standards for judging behavioral and emotional health however; there is an above average prevalence of high school drop-out rate for the urban Appalachian population of Cincinnati (Ludke et al., 2012).

Appalachian children reside in more rural areas, in single parent homes, with lower socioeconomic households, than non-Appalachian children. They are comparable in exposure to secondhand smoke, social support both outside and inside the home, and access to health care services as non-Appalachian children. Both groups have similar lifestyle behaviors however;

Appalachian children are more likely to be covered by Medicaid insurance than private insurance (Ludke et al., 2012).

Due to the health disparities that exist between Appalachians and non-Appalachians identification of this invisible minority is essential to facilitate policies to not only recognize this minority but assist with funding, the development of programs, and research that addresses the needs of this group. Appalachian identifiers need to be incorporated into health information, surveillance systems, and education provided to urban health care providers and public health agencies in the importance of recognizing this group. Most importantly the differences between Appalachians and Urban Appalachians also needs to be considered in practice, research, in the development of programs, and in educational institutions that address the educational and health needs of this group (Ludke et al., 2012).

Screening, Case Management and Follow-up Lead Programs

Screening.

For a screening program to be effective the population that is to be screened must be willing to be screened and find the process acceptable. Low rates of screening reflect barriers which have been supported in the limited literature available on the barriers of lead screening. There is even less literature on barriers of screening in children who have been identified with an ELL.

Screening in public health is a form of risk management that works on the premise of early detection of disease and is often targeted towards high risk populations that are considered statistically more significant for development of a specific disease. There have been many challenges implementing screening programs, with the most common issue being that of a

human concern, of reluctance to use screening programs and the negative effects of participating in screening programs (Beck, 2011).

Medicaid determination of the at-risk population for lead exposure is “children aged < 6 years (especially those aged 0-3 years), pregnant women who occupy homes constructed before 1978, and Medicaid enrolled and Medicaid eligible children” (ACCLPP, 2000, p. 14). Medicaid regulations require that children receiving Medicaid benefits be tested for lead exposure yet nationally only 21% are tested (Polivka, Salberry, Casavant, Chaudry, & Bush, 2006).

The change in recommendations on screening also included that that all children eligible or receiving Medicaid benefits be screened for ELL at 12 and 24 months or between ages 36 to 72 months if they have not been screened before (CDC, 1997; ACCLPP, 2000). Feinberg and Cummings (2005) completed a retrospective study of 675 charts of Medicaid patients between ages of 12-36 months in 7 practices that served mostly Medicaid patients in Kalamazoo, Michigan. Blood lead screening was completed in only 27.6% of the patients. The study found that the patients who did not have results n=489 that 139 (28.4%) were attributable to previous screening, 98 (20.0%) to patient failure, 181 (37.0%) to physician failure, 52 (10.6%) to patient and physician failure and in 19 (20%) cause could not be determined.

The CDC (1997) instituted personal risk questions to assist with the identification of children who are at high risk for lead poisoning if a caregiver answers ‘yes’ or ‘do not know’ to one of the following questions: 1) Does your child live in or regularly visit a house that was built before 1950? (could be child’s home, day care home, or relatives), 2) Does your child live or regularly visit a house that was built before 1978 with recent or ongoing renovations or remodeling?; 3) Does your child have a sibling or playmate being treated for lead poisoning?; 4) Does your child live with an adult whose job or hobby involves exposure to lead? ; or 5) Does

your child live near an active smelter, battery recycling plant, or other industry likely to release lead?

It is interesting to note that the screening question which addressed the age of the home was only accurately answered for 52% children living in pre-1950's housing and only 44% of the children in Medicaid subgroup (Schwab, Roberts, & Reigart, 2003). These investigators used a convenience sample of 200 parents in both private and public clinics in Charleston, South Carolina. Of this sample 25% lived or spent time in housing built before 1950. The researchers believed that these findings reflected the parent's lack of knowledge on the age of the home which limits the effectiveness of this question in identifying children who are at risk.

Testing for BLL in children enrolled in Medicaid in the US increased from 19.2% in 1988-1991 to 41.9% in 1999-2004 periods. Of the children who were tested and who were found to have ELLs only 43.0% had been tested previously during this period (Jones et al., 2009). In the state of Kentucky, the screening rate in children has been consistently higher for children under 3 years than 6 years of age as shown in figure 4.

The state of Kentucky mandates (KRS 211.903) that if a child is a recipient of the Commonwealth's Medical Assistance Program, blood lead testing shall be an eligible Benefit. In addition, testing for lead poisoning shall be made available as part of the regular immunization program offered by the cabinet and shall be provided without charge by the cabinet and by local health departments. Furthermore, at risk children up to 72 months of age should receive a blood lead test if they have not been previously tested. (Clouse, 2010, p. 14)

The screening rates for Kentucky's children receiving Medicaid have increased but are still well below the CDC recommended rate of 100%. In response to the CDC recommendations

of targeted screening the KCLPPP has identified geographic areas of risk. These areas of risk were developed using local childhood prevalence data, pre-1950 housing data and poverty rates for children by zip code. This resulted in the Lead Poisoning Risk Index for every zip code in Kentucky (Clouse, 2010).

The formula used to develop the Lead Poisoning Risk Index is:

$$LPRI=HI+PI+II$$

LPRI=Lead Poisoning Risk Index

HI=Housing Index (percentage of pre-1950 by zip code)

PI=Prevalence Index (percentage of children with lead poisoning by zip code)

II=Income Index (percentage of children living in poverty by zip code)

Zip codes with risk index scores equal to or greater than 52.30 are considered high risk for lead poisoning. A total of 263 of 765 zip codes were found to be at high risk as shown in figure 5 (Clouse, 2010, p. 15)

The screening rates in children under 72 months in Kentucky in the target zip codes areas are higher than children living in non-targeted zip codes however they are still well below the CDC recommended rates as shown in table 6 (Clouse, 2010).

Case management

The CDC since May 2012 recommends that children with $BLL \geq 5 \mu\text{g/dL}$ receive case management services. Case management services are defined as “the follow-up care of a child with an elevated blood level. Case management includes a) client identification and outreach, b) individual assessment and diagnosis, c) service planning and resource identification, d) linkage of clients to needed services, e) service implementation and coordination, f) monitoring of service delivery, g) advocacy, and h) evaluation” (ACCLPP, 2004, p.14; KYHHLPPP, 2012).

Case managers are usually public health nurses who visit the home and coordinate all the services and the implementation of the plan. Case Management includes: 1) Home visiting for visual inspection of the environment for factors that might impact on the child's BLL; 2) developing a written case management plan for temporary lead hazard reduction, permanent lead reduction, temporary or permanent family relocation if necessary, education of the family, plan for follow up medical care and testing, and referrals for Women, Infant, Children, (WIC) or Head Start as well as oversee the activities of the case management team; 3) educating the family about lead and the reduction of exposure to hazards such as dust control, nutrition, hobby or occupational exposures; 4) referring for services for WIC, Head Start or Medicaid; and 5) implementing and evaluating the plan to ensure it achieves the desired outcomes (Koplan et al., 2002; KYCLPP, 2010).

The environmentalist and the case manager must ensure that the interventions are completed in order to reduce exposure by: 1) concentrating on the control of lead hazards; 2) providing prompt interim measures; 3) adhering to safe work practices for lead control so there is no further exposure; 4) removing the minimum required amount of lead paint; 5) enclosing or removing lead building components; 6) clearance testing following lead reduction work; 7) relocating occupants until work is completed; and 8) relocating children permanently if necessary to a lead safe house to reduce exposure (Koplan et al., 2002).

Case managers must consider the elements of exposure when a child has an elevated blood lead level, (EBLL): 1) age and condition of the house; 2) duration of the child's habitation at the present site and a history of residences in the past year; 3) if the residence has been renovated; 4) other possible locations of exposure; 5) lead hazards in the home accessible to the child such as window wells, sills, and other painted areas; 6) soil exposure; 7) dust and dirt

control; 8) relevant child behaviors such as pica and hand to mouth activity; 9) caregiver exposure from hobbies or occupation; and 10) miscellaneous such as water, mini-blinds, cultural practices, and new sources of lead (Koplan et al., 2002).

Lead follow-up screening program.

Public health nurses have identified lack of resources for caregivers as a major barrier in providing lead LFS and making changes in the living environment of lead poisoned children along with not understanding the significance of lead poisoning (Dinsey-Read, 2008). In a qualitative research study by Ames (2007) barriers were identified by providers of families trying to provide for the health of their children. These barriers included; 1) poverty, which was an overarching factor; 2) transportation, which impacted greatly on families keeping appointments, and environmental safe accommodations; and 3) a lack of education and language skills that often resulted in parents failing to act on the health-related information. The providers took some responsibility in admitting that some of the literature and information provided was above caregiver's comprehension level (Ames, 2007).

A study by Polivka (2006) found that 40% of most parents did not recall receiving BLL information and prevention education from providers, 28% of respondents indicated they received a reminder to have their child re-tested, 64% indicated they had not, 7% said they did not know. In a research study by Woolf & Cimino, (2001) a 22-item questionnaire was distributed to assess provider's practices and educational needs in children's environmental health. The survey indicated that providers did not have an adequate knowledge base to address these needs in their pediatric patients.

Sometimes parents avoid having their children screened for lead poisoning or fail to have follow-up lead screening completed. Parents have expressed that if they are not successful at

lowering their child's EBL that again they will lose custody or not be able to stay in their home. Certainly, losing one's child to foster care or not being able to stay in one's home would threaten welfare and security, so they become lost to follow-up (Dinsey-Read, 2006). For this vulnerable group relocating and being able to address this issue is often beyond their financial and social means so they are justifiable in being concerned (Bellinger & Bellinger, 2006).

Parents indicated that they were exposed to lead and that "they turned out alright". There is a sense of disbelief that lead is a serious health issue (Polivka, 2005). Lead hazards are not always detectable to the naked eye with only 1gm of lead dust, or the equivalent of a packet of Sweet and Low, is sufficient to contaminate three houses. Furthermore, health care providers often think that lead is no longer an issue believing that since it has been removed from gasoline and paint that overall population lead level is lower and that lead poisoning is no longer a health concern (Woolf & Cimino, 2001).

One of the issues in the region is that LFS and WIC services are offered collaboratively in Northern Kentucky's Health Departments and when parents fail to return for follow-up they are also not receiving WIC services. A study by Zeroed and Anderson (2004) surveyed WIC enrolled children BLL from 1996 to 2000. Although the findings were not significant, the study did show that BLL declined faster with children who were receiving WIC than children with BLL who were not receiving WIC supplements. Children receiving WIC had an average mean BLL of 7.89 $\mu\text{g/dL}$ (SD= 6.10) in 1996 and in 2000 had a mean BLL of 5.29 $\mu\text{g/dL}$ (SD=4.54). WIC children had a decline of .64 $\mu\text{g/dL}$ at the 95% confidence interval, (CI) = (.36, .91) per year. Non-WIC enrolled children the mean BLL in 1996 was 5.51 $\mu\text{g/dL}$ (SD=4.79) and in 2000 the mean BLL was 3.70 $\mu\text{g/dL}$ (SD= 3.39). The average BLL decline of .42 $\mu\text{g/dL}$ at the 95% CI= (.19, .64). The WIC enrolled children's BLL declined more quickly than the non-enrolled

WIC children but it was not significant ($p=.25$). When the ethnicity was compared with children receiving WIC black children had a significantly quicker decline in BLL than white children did ($p=.03$). The limitation to this study was they were unable to provide ethnic/ racial distribution of children not receiving WIC (Zierold & Anderson, 2004).

Parent Education for Lead Hazard Control

Education interventions are taught to caregivers to assist them to reduce the exposure of their children to residential and other sources of lead hazards (Koplan et al., 2002). Case managers “provide detailed instructions on intervention techniques, actually demonstrate the techniques, and then ask caregivers to perform the technique themselves” (Koplan et al., 2002, p. 101). Parents are educated to control the lead dust hazards by: 1) vacuuming surfaces with HEPA filter-equipped vacuum, 2) wet clean areas with a solution of water and all-purpose cleaner, 3) repaint lead painted surfaces, 4) repair friction and impact surfaces, 5) cover open soil areas with grass or limit access by child, 6) keep child’s hands wiped especially before eating and sleeping, 7) wash toys frequently, 8) block off areas with lead paint so they are not accessible to children (EPA, 1999).

A study by Kegler Crozier and Malone (2004) found that community education, provided by a lay health advisor to the Native American population, in preventative behaviors was significant in reducing children’s mean lead level and increasing preventative behaviors. The study population was divided into two groups because the Superfund County had been exposed to events in the community such as soil remediation and lead education by the Public Health Department which would influence the study outcomes. In the Superfund County BLL declined from 6.0 $\mu\text{g/dL}$ to 4.97 $\mu\text{g/dL}$ ($p=.047$) after an educational intervention. In the Non-Superfund County, the mean BLL went from 4.81 $\mu\text{g/dL}$ to 3.34 $\mu\text{g/dL}$ ($p<.001$).

The study by Kegler Crozier and Malone (2004) targeted four behaviors: hand washing, playing on safe surface, damp dusting, and annual blood lead test. The proportion of Native Americans living in the Superfund County who received annual blood tests went from 14% to 29%, a significant improvement ($p=.019$). Use of a damp cloth also increased in this County from 1.34 to 1.64 after the educational intervention ($p=.015$).

This study also used a comparison population of whites and found that the mean BLL was not significant in difference between Native Americans and Whites. The mean BLL was 1.47 $\mu\text{g/dL}$ among Native Americans and .81 $\mu\text{g/dL}$ among Whites with a significance level of ($p=.238$). In the non-Superfund County, the only behavior that was significantly different was the damp dusting with a difference of .38 for Whites and -.09 for Native Americans ($p=-.004$). The study may suggest that the use of a lay health advisor contributes to the decline of BLLs and the adoptions of some the preventative lead-related behaviors but still require much more study (Kegler Crozier & Malone, 2004).

Lanphear, Eberly, and Howard (2000) looked at the long-term control of lead dust on the BLL of 275 children in Rochester, New York. These children and their families were randomly placed in a control or an intervention group. The intervention group received cleaning equipment and up to 8 visits from a trained lead hazard control advisor. After 48 months the intervention group was 5.9 $\mu\text{g/dL}$ (95% CI=5.3, 6.7) and the control group 6.1 $\mu\text{g/dL}$ (95%CI= 5.5, 6.9) and was not significantly different ($p=.73$). The findings of this study do not indicate that control of lead dust is an effective method for prevention of childhood lead exposure. The authors of this elaborate on this theme to add;

These results underscore the fact that dust control, one of the primary strategies to control lead exposure for children with low to moderate elevations in blood lead concentration,

does not seem to be effective unless it is performed by professional dust control teams.

Taken together, these and other data indicate that we can no longer rely on dust control, as performed by families, as a panacea to prevent sub clinical lead toxicity in children.

(Lanphear, Eberly, & Howard, 2000, p. 4)

Lost to Follow-up

Appropriate follow-up measures require that patients are notified within 10 working days of receipt of the report. Clients receive follow-up when he/she has; abnormal test results, been referred to another provider, missed a return appointment, referred from one local health department(LHD) to another, or a pregnant client, who must have a designated prenatal care provider documented in the chart, to receive non-prenatal services at an LHD (Kentucky Cabinet for Family and Child Services [KYCHFS], 2006). Documentation of all contacts made or attempted and return appointments scheduled are documented in the client chart. Any appointments that are not attended, without notice, are considered a ‘no show’ and are documented as such. Any telephone calls made to /or from the patient or a provider regarding patient care is documented along with; 1) reason for the call, any problems by client or provider, 2) action taken or advise/ instructions given, and 4) date and time of the call. Timing guidelines for these activities are further defined by state or federal guidelines depending on the health condition (KYCHFS, 2006).

Guidelines for follow-up

The guidelines for follow-up are recommended by the KYCHS. These guidelines include a minimum of three attempts to notify patients as follows. For those uncontactable

1. Initial contact made by telephone if number is available and permission given by client for home contact.

2. Second contact should be a regular mailed letter with directions for contact to LHD for follow-up.
3. Third should be a certified or registered letter with directions for contact to LHD for follow-up.
4. Client not contactable by the above measures, a home visit is strongly recommended for results that are potentially life threatening.
5. After three attempts and no contact by client, or three appointments made but not kept the LHD provider should document this in the chart and the client is lost to follow-up care.
6. When patient is referred to a private medical provider follow-up becomes the responsibility of the provider except for cancer programs.

(KYCHFS, 2006).

Foundational Concepts: Health Decision Making, Treatment Engagement and Health Literacy

The process of decision making and the Health Belief Model (HBM) are in this literature review to help inform the researcher and are not being used as a framework. The study's focus will explore the decision making of caregivers of lead poisoned children in remaining engaged in LFS.

Decision making

Decision making is broken down into five stages. Stage one, is *Appraising the Challenge* where by an individual is faced with some disturbing information or event that may result in loss. Stage two, is *Surveying Alternatives* results when an individual's confidence in the old policy is challenged and begins to search in his/her memory for alternative solutions and seeking advice

from others as a way of coping. Stage three, *Weighing Alternatives*, the decision-making process for the individual now includes a list of viable alternatives and focuses on a more thorough evaluation of these alternatives weighing the pros and the cons. Stage four, *Deliberating about Commitment* the decision maker has covertly decided on a plan of action and now deliberates on how to institute this plan, as well as, tell others of his/her intentions and considers the potential feedback to his/her decisions from others. Stage five, *adhering despite Negative Feedback*, during this stage the decision maker may experience the honeymoon phase where he/she is quite satisfied with the decision. Within time however; this new position may be challenged with new threats or opportunities and stage five become stage one again. However, Stage five can be different than stage one in that if the challenge is powerful enough, has shaken the individual, and the risks are high enough the individual may stick with the original decision (Janis & Mann, 1977).

Health decision making

There are numerous theories that explore health protective behaviors and frameworks that can assist with the interpretation of caregivers who choose to remain engaged with LFS and those who do not (e.g. Bond & Nolan, 2011; Weinstein, 1993). Several models have been developed to assist with the interpretation of how health protective behaviors are adopted however the Health Belief Model (HBM) has been the simplest, the most used and tested in health education and health promotion (Becker, 1974; Rosenstock, 1974a; Glanz, Rimer, & Lewis, 2002). HBM has also been useful in explaining, predicting the preventative behaviors such as screening, illness behaviors and behaviors related to chronic diseases observed in caregivers of lead poisoned children (Becker, 1974; Rosenstock, 1974a).

The HBM was developed in the 1950s by a group of social psychologists in the U.S. Public Health Services to understand the failure of many people to embrace disease prevention and screening tests so asymptomatic diseases could be detected early. Later this same model was applied to patients' responses to symptoms and whether they were compliant with the recommended medical regimens (Janz & Becker, 1984).

The HBM has two basic variables that were developed using an extensive body of knowledge from psychological and behavioral theory. The first variable is the value the individuals place on a goal and the second is the individual's estimate that an action will achieve this goal. When considered as health-related behaviors these variables are conceptualized and the desire to avoid illness or if ill to become well again and a personal action that will reduce the threat of illness (Janz & Becker, 1984). The HBM has four dimensions:

- 1) Perceived susceptibility- Individuals perception of vulnerability to a condition. Thus, the individual's perception of risk at contracting the condition.
- 2) Perceived Severity- Individual's assessment of how serious the condition is and the consequences of that illness including social consequences.
- 3) Perceived Benefits-Individual's assessment of the positive consequences of adopting a behavior that would reduce the disease threat.
- 4) Perceived Barriers-Individuals assessment of the negative aspects of adoption of a health action or recommended behavior. A cost benefit analysis occurs to assist the individual in determination of adoption of an action (Janz & Becker, 1984; Marks, Murray, Evans, & Vida Estacio, 2011).

The combination of susceptibility and severity levels provide the force for the individuals to act and the perception of benefit (less the barriers) provide the path of action (Rosenstock, 1974b; Janz & Becker, 1984).

Some form of trigger needs to occur for action to be taken and the decision-making process started. This trigger is known as the ‘cue to action’ and could be internal from a symptom that an individual experience or an external cue perhaps from interpersonal or mass media communication or a reminder message from a health provider. Demographics such as age, sex, socioeconomic status psychosocial factors such as personality traits, peer influence and family (Marks et al., 2011; Janz & Becker, 1984).

In 1988 self-efficacy was added to the HBM’s four beliefs. Self-efficacy is the belief in one’s ability to have a level of performance and influence over events in one’s life. Self-efficacy determines how people think, what motivates them, and how they behave. This includes cognitive, motivational, affective and selection processes (Bandura, 1994). The sources of self efficacy include:

- 1) Performance accomplishments: past experiences of success and failure,
- 2) Vicarious experience: witnessing others’ successes and failures
- 3) Verbal persuasion: being told by others that one can or cannot competently perform a behavior
- 4) Emotional arousal: when engaging in a behavior in a specific situation.

(Marks et al., 2011, p. 132)

Treatment engagement

Treatment engagement is defined by the Center of Advancing Health (2010), as “actions individuals must take to obtain the greatest benefits from the health care services available” (p.

2). Many treatments require clients to return for multiple appointments and play an active role in their recovery. Commonly treatments for depression, eating disorders, physical therapy, regimens after surgery and other procedures, substance abuse, skills training, and weight loss programs are structured in a manner that requires multiple appointments and activities for a positive outcome (Geers, Wellman, Seligman, Wuyek, & Neff, 2010). When reviewing the literature for engagement other terms such as adherence, compliance, and participation were used to describe clients who stayed in treatment, and attended appointments (Littell, Alexander, & Reynolds, 2001). Compliance however is not the same as engagement and this distinction is very important as LFS requires caregivers to attend follow-up screening but to achieve the desired outcome must be acting on the lead hazard control recommendations, cleaning, following the diet recommendations, and limiting the child's exposure to lead. When an individual is engaged, they are involved in the process and use information and professional advice to meet his/her own needs and preferences, increase their ability to prevent, manage and cure disease. With compliance or adherence, the individual obeys the directions of the health care provider versus being a participant in engagement in their treatment (Center for Advancing Health, [CAH], 2010).

Factors that impact on engagement behaviors are very complex and reflect the individual's characteristics such as age, self-efficacy, and literacy. Disease characteristics such as acuity, co-morbidities, and treatment demands and characteristics of the setting, such as type of provider, information that is available and cultural norms also impact on engagement (CAH, 2010). Engagement of a caregiver on behalf of their child is even more complex especially in underserved populations.

The literature that considered pediatric and caregiver or family engagement dealt with the delivery of mental health and adjunct services to families (Staudt, 2007). Children and their families in these service areas were found to have high rates of ‘no shows’ or ‘premature terminations’ across all populations (Staudt, 2007). Of families who received services for abuse and neglect, only 30% received traditional family therapy and 62% group therapy had planned terminations (Meezan & O’Keefe, 1998). In urban mental health clinics serving minority and low-income families, 36% of families who requested services did not attend the appointments and 45% of families who had used services previously did not keep their appointments (McCay, Pennington, Lynn, & McCadam, 2001).

For children who were survivors of childhood cancers follow-up is essential for monitoring treatment relapses, secondary malignancies and late effects of treatments (Oeffinger & Hudson, 2004). Up to 70% of childhood cancer survivors will develop a chronic medical condition in their lifetime so follow-up is essential (Geenen et al., 2007; Oeffinger et al., 2006). Only 42% of cancer survivors indicated that they had attended cancer related follow-up in the past 2 years in the Childhood Cancer Survivor Study (Oeffinger et al., 2004).

Treatment engagement for caregivers of at risk children have also been identified as having two components, behavioral and attitudinal. In the behavioral component, the client’s performance of tasks assists with the treatment and results in the achievement of health outcomes. The tasks in this component would include appointment keeping, completing homework, discussing feelings, responding to requests made by the practitioner (Karver, Handelsman, Fields, & Bickman, 2005).

The second component of engagement is attitudinal which is the emotional investment and commitment to treatment. This requires the client to believe that treatment is worthwhile

and that there will be a benefit. As a result, the client becomes emotionally invested in the process, and has a positive attitude and feels that it is worth the time and energy to follow through to completion. Part of this investment means the client must be ready for treatment in the context it is provided. For underserved families, personal and environmental stresses are often so great that the perceived ‘costs’ of treatment outweigh the ‘potential benefits’ (Webster & Stratton as cited in (Staudt, 2007).

This concept is illustrated by a study which examined the factors that contribute to post-treatment follow-up care for survivors of childhood cancers. The following sociodemographic information was collected: patient’s gender, current age, ethnicity, distance lived from the hospital (>56.7 km), type of insurance, patient age at diagnosis, type of cancer and treatment modality, time off treatment, relapse, clinical trial protocol, and follow-up care through to 2009. The cohort included 173 children (98 male, 75 female), ages from birth to 18 years. The mean the number of years at diagnosis for males was 7.67 versus 13.20 years for females in 2009. Each of these children had been diagnosed with cancer in 2004 and treated at a Children’s Hospital. The information was collected through the tumor registry and medical charts at this hospital (Barakat, Schwartz, Szabo, Hussey, & Bunin, 2012).

In this study a linear regression model analysis was used to predict the total of number of follow-up visits. The full model was significant [$F(12, 160) = 3.49$, $R^2 = 0.21$, $p < 0.01$] with type of cancer, patients with solid tumors ($\beta = -0.29$, $p = 0.006$), brain tumors ($\beta = -0.23$, $p = 0.010$) attended less follow-up appointments than clients with leukemia/lymphoma. Factors that were also significant for the number of follow-up visits were treatment modalities ($\beta = -0.15$, $p = 0.073$), relapse ($\beta = 0.2$, $p = 0.009$), and distance from hospital ($\beta = -0.21$, $p = 0.006$) (Barakat et al., 2012).

The full model of the 5-year post diagnosis period was significant [$F(12, 160) = 4.52$, $R^2 = 0.25$, $p < 0.001$]. Factors such as the non-white race ($\beta = 0.27$, $p = 0.001$), having public insurance ($\beta = 0.25$, $p = 0.002$), and treatment modalities ($\beta = 0.14$, $p = 0.085$) were predictive for the total number of no shows in the 5-year follow-up window. Within the total sample there were 25% who had completed treatment but had never been seen for follow-up in the 5-year post diagnosis window (Barakat et al., 2012).

The authors found that sociodemographic factors were predictive of whether a patient would return for follow-up cancer care. These findings were also confirmed in other studies from cancer survivors. Factors such as non-white, distance to hospital, male gender, and public insurance are risks for reduced engagement in follow-up care (Barakat et al., 2012). These variables were not just limited to cancer survivors but have also been identified in a framework explaining the impact of sociodemographic in health disparities through the National Institute of Health-sponsored Centers for Population Health and Health Disparities (Warnecke et al., 2008). With the risk factor of relapse, the research found that many caregivers were more likely to experience post-traumatic stress disorder (PTSD) and other health problems due to the continuation of illness of their child. During caregiver's treatment and follow-up, as well as, the child's treatment they are more likely to be re-educated about the late effects of cancer care on cancer survivors, the importance of follow-up, and more integrated into care clinics. The total overall 'no shows' demonstrates an overall lack of engagement in the follow-up process (Barakat et al., 2012).

Health literacy

To remain fully engaged in LFS, caregivers must be able to fully utilize the information that is given to them, and decide how it applies to their situation, and make the determination

based on their circumstances on whether LFS is beneficial to their child or not. This is known as information or health literacy. Low literacy skills have been linked both indirectly and directly with poor health outcomes (Parker, 2000). Low literacy levels have also been linked with diminished use of health information and disease prevention services, as well as, poor self-management of disease and these individuals were 1.5 to 3 times more likely to experience adverse health outcomes (DeWalt, Berkman, Sheridan, Lohr, & Pigone, 2004). Those who experience low literacy are more likely to be in poor socioeconomic circumstances which in turns impacts on health outcomes that has been found to be independent of all other risk factors (Nutbeam, 2008).

The World Health Organization (WHO) defined health literacy as a representation of “cognitive and social skills which determine the motivation and ability of the individual to gain access to, understand, and use information in ways that promote and maintain good health” (WHO, 1998, p.10). Cognitive, critical thinking, analysis, decision making and problem-solving skills, along with social communication and questioning, allows for the empowerment of the individual to improve their health status and that of the community in which they live (Speros, 2005). Individuals with low health literacy struggle to master the language of the health care provider and when unsuccessful may feel contempt and a sense of disempowerment (Adkins & Corus, 2009). Increasingly health care has moved toward consumer-directed health care, a move that has been criticized because of the assumption that consumers are able to take control of their health care. Low literate consumers may not be able to make these complex decisions especially when presented with the treatment and alternative options plus risks and benefits of both (Adkins & Corus).

Health literacy developed by Nutbeam (2000) includes three levels:

- Level 1 (functional health literacy)-basic reading and writing skills that can assist an individual to function in the health care arena. Activities in this category include communication of information for health risks and health care utilization.
- Level 2 (interactive health literacy)-refers to personal skills that an individual develops to improve personal capacity so that the individual can act independently when knowledge is given. Activities in this category include health communication, community self-help, and social support groups.
- Level 3 (critical health literacy)-refers to an individual being able to critically evaluate and use information to participate in health promotion activities. Activities in this category are cognitive and social skills development as well as capacity building to enable individuals and communities to act.

Studies that look at health literacy in parents have found negative child health outcomes (Betz, Messke, Ruccione, Smith, & Chang, 2008). A systematic review of literature found that low parent literacy is related to worse health outcomes for their children. Behaviors such as smoking, violence, and lack of breastfeeding were more commonly a result of societal influences and not low literacy. Behaviors such as adherence, correct dosing, and ability to access medication are directly linked to the ability to read and understand health information and instructions. The authors found that there were mixed results from studies and more research needs to be carried out on the role of health literacy and health outcomes especially in children under the age of seven (DeWalt & Hink, 2009).

A study that considered the health literacy of US parents and explored the role of health literacy in mediating child health disparities found that a large portion of US parents have limited health literacy. A sample of US parents (n=6100) represented the 72,600, 098 US parents from

the National assessment of Adult literacy completed in 2003. Parents were assessed on 13 child-health related tasks. The finding indicated that 28.7% of parents were below- basic/basic health literacy, 68.4% were unable to enter names and birth dates correctly on health insurance forms, 65.5% were unable to calculate the cost of an insurance policy required for the family based on size and, 46.4% were unable to perform 1 or 2 medication related tasks. In this study parents who were in the below- basic literacy category were more likely to have a child without health insurance (adjusted odds ratio: 2.4[95% CI 1.1-4.9]) than parents who had proficient literacy. Parents with below-basic literacy reported having difficulty understanding over the counter medication labels (3.4 times the odds, 95% CI 1.6-7.4). Health literacy was found to account for some of the effect on education, racial/ethnic, immigrant status, linguistic and income related disparities (Shonna Yin et al., 2009).

Summary

The review of literature has discussed lead exposure as one of the most significant environmental child health and developmental issue in the US. Even low levels of lead exposure have resulted in significant childhood cognitive impairment and behavioral issues (Canfield et al., 2003). Thus, it is imperative that children with ELL and their caregivers remained engaged in LFS programs. Kentucky Childhood Lead Poisoning Program Director, case managers and clinic nurses in the Northern Kentucky region have identified ‘lost to follow-up’ or failing to remain engaged in LFS as an issue. Other studies following lead level screening and timing for declines of lead levels have also identified significant attrition rates in LFS and LFU in other regions of the U.S. Better understanding of the decision-making process caregivers undergo to remain engaged in a lead follow-up program will help the development of lead screening programs and interventions that meet caregivers and their family’s needs. Treatment Engagement

and Health Literacy will be used to frame this study's focus on exploring the decision making of caregivers of lead poisoned children in remaining engaged in LFS.

Chapter Three: Methodology

Design

Grounded theory is an appropriate framework when the research problem requires a development of a theory; a process requires explanation, or interactions and actions of individuals that need to be developed into abstract concepts (O'Neil Green, Creswell, Shope, & Plano Clark, 2007). For the research questions exploring the decision making of how caregivers decide to remain engaged in LFS and the social processes and contexts influencing the decision-making processes GT is an appropriate method.

Qualitative, grounded theory guided the methodology, sampling, data collection and analysis of this study. Grounded theory assisted “the researcher in moving beyond description of the domain of study toward a theoretical rendering that identifies key explanatory concepts and the relationships among them” (Wuest, 2007, p. 240). Grounded theory is useful in the practice of nursing as it allows for the “explanatory theories of human behavior within social context” (Wuest, 2007, p. 240). For lead poisoned children and their caregivers grounded theory is a rigorous qualitative method in determining how caregivers operationalize meanings and how these meanings are integrated into action to remain or not remain engaged in LFS programs.

Explanation of Grounded Theory as a Process

Explanation of Grounded Theory as a process is reviewed in detail and can be found in Appendix A.

Protection of Human Rights

Approval was obtained from the University of Hawai'i at Manoa Institutional Review Board (IRB) as shown in Appendix B and has been obtained from the Northern Kentucky Health Department Review Board. Consent to participate in the study was obtained from each

participant before the interview begins as shown in Appendix C. Confidentiality of all tapes and records were observed and the contents of the interview, both audiotapes and transcripts were kept in a locked cabinet and the key in the possession of the researcher. No participants' name or any identifying factors was used when reporting the study results. The participants at any time had the right to stop the interview and were informed of this right before the interview began. The participants were given a gift card for \$ 15.00 from a grocery chain at the interview time and their name was added in for a drawing for a \$100.00 gift certificate. If the participants choose not to complete the interview they were informed they would still receive the gift card and the opportunity to participate in the drawing. The outcomes of the study were shared with any participant who was interested in receiving the results.

Population and Locale Description

Background of the urban region population and setting

The demographics of the region that is served by the Local Health Department (LHD) and the sample that will be drawn are; 95% white, 2.5% Black, 0.7% Asian, 1.3% Hispanic and 1.6% other (Northern Kentucky Health Community Health Committee, 2002). The LHD does not break ethnicity down further but the Greater Cincinnati Community Health Status Survey reported that 47% of the Greater Cincinnati population had Appalachian heritage. This heritage was determined by the identifier type of first generation Appalachian based on state and county of birth, first or second generation based on county and state of parent's birth, others self-identified as Appalachian, while others had family roots in Appalachian regions (Ludke, Obermiller, Rademacher, & Turner, 2012).

This researcher used the LHD lead logs, case managers and clinic nurses to access caregivers who have experienced or who were presently in the process of LFS in the Northern

Kentucky region. The children were age six or under and had a blood lead level that was 5µg/dL or greater and had at least two lead follow-up testing screening visits. The children resided in the Northern Kentucky region. The *City of Covington and Northern Kentucky Home Consortium*, (2008) includes these target zip codes and detailed demographics for this region are available. It is important to note that 35.5% of families with children are headed by females in the consortium and that one major city in the consortium has the third highest female headed home in the United States as shown in Table 8 (P. Baker personal communication, November 2011; (Northern Kentucky Home Consortium [NKHC], 2008).

The total population in the Consortium area is 78, 117 with a breakdown of 51% female and 49% male. There are a total 5,468 female headed of household with no spouse in the Consortium as shown in Table 7. In the NKHC region 59% of minorities are concentrated in census tract 671 and 22.3% and 21.3% respectively in census tracts 501 and 502. These census tracts have the lowest median incomes of the entire Consortium at \$ 10,624 and \$11,420 (see Appendix B & Table 7). In the Consortium 38.4% of the Black families live in poverty compared to 17.9% of all families and 15.9% for whites. Approximately 35.9% of Hispanic families also live in poverty (NKHC, 2008).

Northern Kentucky borders on the Ohio State line, with industrialization as early as 1834 with reports of a nail factory, two cotton factories, a sawmill, five tobacco and cigar factories, two distilleries, and a brewery (Kentucky Educational Television [KET], 2009). Because of this early industrialization sizeable neighborhoods with large Victorian homes were developed. These homes at one time were occupied by middle to upper income families who could afford to use the “best” lead paint but now these homes have deteriorated and have lead paint hazards. Many of the white families who lived in these homes moved into the suburban areas. This

movement is known as the “white flight” and these early neighborhoods now have lower family incomes, property values, and tax base for schools. These original homes are now multi-unit homes for families who are mostly minorities and impoverished (Hanchette, 2007).

Sample

A purposive sample of caregivers who had a child with an ELL who had at least two lead follow-up screening appointments were invited to participate in the study. Sampling was based on the caregiver and child’s unique experiences within the LFS. The study consisted of 15 interviews, 16 participants, 2 males age 25 years and the other 45 years old. The 14 female participant’s ages ranged from 23 to 56 years of age. Other demographics were collected about the participants including marital status, race/ethnicity education level, household income, use of WIC, age of home, whether home was rented or owned, number of children living in the home, the number of children with verified elevated lead levels and whether the elevated lead level was a result of the home the child was residing in (see Appendix G).

Significant demographics that are considered significant to this study include 14% of participant had less than a high school education, 36% had a high school degree and 29% had some college, 21% had a college degree. The household income was also significant with of the 36% participants had a household income (HI) less than 5,000 per year, 7% had an HI between 5,000 to 10,000, 21% HI 10,001 to 15,000, 14% HI 15,001 to 20,000 and 7% HI 20001 to 25,000, 14% declined to report. Other significant information captured 93% used WIC services and 71% rented the home they lived in (see Appendix G).

During the interview process as the data was analyzed the researcher move to theoretical sampling to capture relevant data to saturate the categories and their properties (Glaser & Strauss, 1967; Charmaz, 2006). Case managers assisted in the identification of some potential

participants and a letter was mailed inviting individuals to participate in the study. After two weeks a second follow-up letter was sent reinforcing the purpose of the study and the potential participant was asked if they were interested in obtaining more information or participating in the study. Initially the plan was to follow up with a contact by phone however many of the phone numbers were not working and a few participants thought it was the Health Department contacting them. The one issue this researcher did find in recruiting was there would be a flood of responses all at once. If any period elapsed between the time of initial contact and interview the participant often did not participate. As a result, many of the interviews were completed in clusters. This resulted in little time to analyze the data if at all between interviews. This seemed to be reflective of the population and the need for monetary benefits. Screening for elevated lead also occurs in clusters so this also contributed to this issue.

A second issue that the researcher found that quarter way through the research period KY Statute 922 KAR 1:330 Child started to be consistently enforced where in the past it had not been. This statute includes “Medical Neglect, in accordance with 42 U.S.C 5106a(b)(2)(C), if any child has not received a medical assessment or is not receiving treatment for an injury, illness, or disability that if left untreated may” a) Be-life threatening; b) Result in permanent impairment; c) Interfere with normal functioning and worse (Child Protective Services, 2018). This resulted in almost all caregivers with children ELL participating in LFS.

Setting

The time and setting of the interview was determined by the participant so that they were comfortable, open to talk, and free from distractions. The researcher also had access to a private room in the LHD, as well and most of the participants did have their children present due to

daycare needs. Interviews were conducted per participant's request in the client's homes, outside client's homes on porches, allies, backyards, LHD private room and by telephone interview.

Data Collection

Before any data was collected, the purpose of the study, the consent, and use of the data was explained to the participant. Permission to audiotape the interview from all participants was obtained and participants who requested phone interviews permission was captured on the audiotape. All procedures were reviewed and explained as well as the right of the participant to withdraw at any time. Participants were given a copy of the consent form and those who interviewed via telephone were mailed the consent.

Data was obtained using semi-structured interviews with a question interview guide developed by the researcher. DeVellis (2003) survey development outlines were used and were informed by the literature as shown in Appendix D. The initial questions developed were reviewed for content validity by experts in the field: 1) Quality Manager, LHD; 2) Director of Clinical Services, LHD; 3) Director of the LHD; and 4) a participant in the KYCLPPP. Questions were added to the guide, after discussion by the researcher and the second rater when a category required more comparison and further analysis as laid out in the process for theoretical sampling. Additional questions added are shown in appendix E).

The child's HD chart was reviewed, with permission of the caregiver after the interview, for blood lead levels, timing between visits, case management, environmental home visit results, and other health department visits such as WIC and Well Child visit, and any other pertinent data as shown in Appendix E.

Basic social-demographic information and history of the child's lead poisoning and living environment was recorded by the researcher during the interview, by asking the caregiver

questions, before the interviews start as shown in Appendix F. At the beginning of the interview general questions were asked with probing questions afterwards for clarification (Wuest, 2007). Field notes were recorded after the interview with information such as location and length of the interview, who else is in attendance with the participant, the general surroundings of the community and home, and any other significant incidents that allowed a glimpse into the participant's life (Wuest, 2006). As the emergent data was obtained and the study evolved additional open-ended questions were added.

Data Management and Analysis

The interviews were transcribed verbatim and set up in a two-column format with raw data on the left of the margin and room for comment insertion and theme development on the right. The transcribed interviews were read by the researcher and the second rater separately and codes were applied at the word, line to line and incident to incident (Wuest, 2007). Next notes were inserted, and labels were added with the first three interviews. Raters met face to face and had discussion about the emerging data, and codes were held with minutes being recorded. Further interviews were conducted, and the interview was sent to both raters to review individually. Face to face meetings were held after approximately every two to three interviews to discuss codes, analyze findings and the group of codes with minutes being recorded. This process continued with both raters working as a group and diagramming and reduction (Charmz, 2006). Categories were developed from the emerging data and diagramming was carried out for the establishment of patterns for consideration by each rater and again face to face meetings allowed for the presentation of the rater's findings. The data was read and re-read numerous times to reduce the data. Once themes emerged the categories were further scrutinized by memo writing and reviewing data for missed findings or further validation. Theoretical sampling

continued to provide further clarification, to saturate the concepts and clarify relationships (Wuest, 2007).

This researcher used journal diaries to record reflexive accounting to enhance credibility and to help manage boundaries. The use of support from another colleague, advisor and second rater, who had extensive public health and qualitative research experience, but not lead case management experience which assisted with the task of addressing reflexivity (O'Neil, Green, Creswell, Shope, & Plano Clark, 2007).

Reliability of data analysis was enhanced through using a second rater for coding and analysis of the data. Again, this experienced qualitative researcher was able to question the researcher about assumptions, findings, categories for clarification, explanation and analyzes. This assisted the researcher in identifying concepts that were case management related, unspoken assumptions and provided an opportunity to explore these openly and with this awareness while the analysis of the transcripts and establishment of codes was conducted. This allowed for an external check on highly interpretive data (Creswell, 2007). The other benefit was the second rater was able to identify and/or question concepts that were identified by the experienced lead case manager and obtain explanations for inclusion or exclusion in the data set. Creswell (2007) outlined the following steps to achieved and establish intercoder agreement.

- Transcripts were read through multiple times by each coder independently and coded.
- After analysis of 3 to 4 transcripts the coders met and examine codes, their names, text segment, and minutes were established on how coding determinations were made.
- These minutes were used as a stable representation of the coding analysis for all coders.

- After each three additional transcripts the coders met again, and codes were compared as well as important agreement on text that is assigned. The coders determined that lines would be counted if some portion of the data in the line was deemed important.
- The decision of intercoder agreement is a yes or no agreement and the goal is to achieve an overall 80% agreement on coding (Creswell, 2007; Miles & Huberman, 1994). Creswell (2007) also recommended that researchers may also want to use a kappa calculation. With the use of two coders the results will range from 0% to 100%. Cohen (1960) kappa coefficient k was used for this calculation as it relates to the number of concordant ratings to the number of discordant ratings and considers the number of agreement ratings by chance. Cohen's kappa calculation results in values between -1 and +1. A +1 indicates absolute agreement among coders and 0 is incidental agreement anything below 0 indicating agreement worse than chance. Intercoder agreement was calculated by a regional level three statistical center and kappa values between .41 and .60 were accepted as agreement.

A Kappa analysis was performed on all the lines with all the participants combined. The lines were assumed to be independent of each other even though they were not because they were prepared by one person for one participant. The resulting Cohen's Kappa κ was 0.067 which represents the proportion of agreement over and beyond the agreement by chance. An analysis on the proportion correct was performed again assuming the lines were independent of each other, which may or may not be true as stated above. A confidence interval for the proportion of lines that were in agreement was $82.4\% \pm 1.5\%$ or between about 81% and 84%.

Coder 1 and 2 agreed $24.5\% + 57.9\% = 82.4\%$ of the time. At least one of the coders found $24.5\% + 13.3\% + 4.3\% = 62.9\%$ of the lines to be important. Furthermore, the p -value was < 0.0005 which suggests that our Kappa value is significantly different from 0 (see Table 9).

The first time the analysis was run a significant discrepancy was found in one transcript. Upon returning to the transcript it was found that a portion of the interview had not been coded. This was corrected, and the analysis run again. This process also serves as a check to ensure data quality. A second tool was also used to examine the language used by the participants. Looking at the data by examining in vivo codes or what is known as the participant's special terms or meaning in the language they use when they share their story (Charmaz, 2014).

The analysis continued with axial coding as it relates to the categories and subcategories to bring back the data into the whole (Strauss & Corbin, 1998). This is done by also answering the questions when, why, who, how and what consequences and using set of scientific principles that Strauss and Corbin suggest; 1) conditions, 2) actions/interactions., 3) consequences (1998).

Summary

This chapter discussed the use of grounded theory as an appropriate framework when the research problem requires a development of a theory. Caregivers, with children experiencing lead poisoning, are involved in a process to help mitigate the long term impacts of this illness. Understanding the decision making process as well as the social contexts for remaining in case management and LFS is important for the improvement of nursing practice and impacting on children's health outcomes with lead poisoning.

Chapter Four: Findings

In this chapter the findings of the “A Caregiver’s Decision-Making Process in Remaining Engage in a Lead Follow-Up Program with a Child with an Elevated Blood Lead Level” are reported. A constructivist grounded theory methodology was used to answer the research questions; 1) What are the decision-making processes caregivers undergo to determine if they will remain engaged in the lead follow-up screening program?, 2) What are the social contexts and processes that influence the decision-making processes that caregivers undergo to determine continued engagement in a lead follow-up screening program?

The concepts reflect the perspective of the participants who discussed the process they experienced in the decision-making process to remain engage in lead follow up program are; *Psychological Reactions*, *Parental Coping*, and *Meeting expectations*. These concepts describe the process that caregivers experienced in the journey of trying to address an ELL in their child. Each of these concepts were cyclic, none are static and play a significant role, and in the decision making process of whether to remain engage in LFS, see figure 7.

Core Category: Tells you if what you are doing is working

The core concept of *Tells you if what you are doing is working* is an “in-vivo” code and came directly from the responses from the participants and is reflective of the social world and organizational settings known to the participants (Charmaz, 2014). This phrase or something very similar was used to describe the purpose caregivers indicated in the intention to return or remain in LFS even though caregiver indicated there were many barriers and issues surrounding this process. Caregivers indicated that LFS assisted them in meeting the expectations placed on them as their role as caregivers, as well as, social and health care system expectations. Some phrases used by participants that illustrate the core concept include:

“I want to know what I changed—they ask me did I change anything that it (lead) went down.”(Participant # 3).

“Checking-on the right path-it goes down. Major defeat- it goes up” (Participant # 2).

Some participants did not actually see the value of the LFS however they were not willing to risk not attending LFS. These responses included:

“Even though it might not be necessary, it’s still worth a try. There’s that chance.” (Participant # 8).

“Well I do it anyways just ‘cause I think it’s best for my son. I wanna make sure that he’s getting it out of his system and it’s not gonna cause him further damage”(Participant # 9).

Caregivers recognized that it was a duty, part of the role expectation and this role included being responsible for the health and well being of the child and part of the process to addressing the child’s ELL:

“No, I mean, not really. I would still do it. That’s my baby’s health, and I know the effects of it, so I would feel so bad if I got lazy and didn’t wanna do it and he needed it” (Participant # 8).

Caregivers expressed that when the child did not appear to be sick they did not understand the perceived risk to the child so did not really need to see if her lead level was lower. This illustrated a lack of understanding of the purpose of screening and how it can impact on the parent’s understanding of the control of lead hazard

“I’m going to be truthful. I did not take her there. It’s important, but it is a sickness you don’t see. She’s normal she is running around, whatever. I think I didn’t take it that

seriously after you see she's normal or whatever. Eventually I took her of course
(Participant # 3).

Psychological Reactions

The first theoretical concept identified from the participant's responses is, Psychological *reactions*. Caregivers described many psychological reactions throughout the treatment course with their child with an ELL. Psychological reactions is reported to have three dimension. The three dimensions include *discovery, psychological involvement with the child, and long term fear and anxiety, guilt and stigma*. Each dimension is described below.

Discovery.

The first dimensions is *discovery*, the initial psychological reaction when the caregivers were first told about the child's ELL and the treatment regime to mitigate the risks. Some common words that were used by caregivers to express themselves included freakin' out, worried, concerned, horrible, overwhelmed, and the horrors of lead. The first dimension of discovery was described as that first psychological response, the reaction to finding out about the child's ELL. The reaction was not just limited to the first time. Caregivers also expressed similar reactions if the BLL had been coming down and then jumped:

"It completely freaked me out.... It scared me. It scared me to death" (Participant 5).

"I just didn't understand what it was at first: I didn't know how to get it"

(Participant # 9).

This caregiver indicated she had a significant psychological response to the news of an ELL, she was unaware her children had high lead levels, had moved, and was told after being tracked down by social services:

“It was horrible and because.... we found out through Child Services. We didn’t know before that (Participant # 11).

The discovery reaction was also impacted by previous knowledge of lead poisoning that caregivers already held:

“Concerned because my cousin had the lead poisoning and it messed with her brain, so she can’t read that well when she types her words kinda like miss worded” (Participant # 1).

Participants indicated the initial reaction was often more significant depending on what information was given to them and how it was communicated:

“I cried because of the whole-the way they tell you. It’s not all, he had lead level. The first thing comes first is he may have brain damage. He may have something wrong with him. It’s not decent, the gentle touch of, “Hey, he has lead” (Participant # 5).

Psychological involvement with the child.

The second dimension is *psychological involvement with the child*, which includes empathy, feeling protective towards the child, and advocating for their wellbeing. The caregivers also felt guilty for not being able to protect the child from lead poisoning and the child having to endure LFS. The caregiver wanted the wellbeing of their child considered during invasive lead screening and the coordination and frequency of testing to be minimized. The second dimension is *psychological involvement with the child*, which includes empathy, feeling protective towards the child, and advocating for their wellbeing. The caregivers also felt guilty for not being able to protect the child from lead poisoning and the child having to endure LFS. The caregiver wanted the wellbeing of their child considered during invasive lead screening and the coordination and frequency of testing to be minimized. The second dimension of

psychological involvement with the child highlights the reactions, caregiver's experienced, and that result from role expectation and wanting to protect the child:

"It is rough, it rough, because my daughter was always getting her finger poked every month and she didn't like it and then that makes me feel bad (Participant # 1).

"I cringe I feel like; the hotness comes over me again ... I feel defeated ... I try to do everything you know you try not to let your child be sick at all and it is kinda like what can I do more for him to get this ... (huge sigh) (Participant # 2).

Caregivers worry that the child's chronic lead will impact not only their health but how they perceive the world. Caregivers want a normal childhood for their children and quality of life for the family.

Yeah, I still have worries about-actually, about his behavior. The doctor told me his high lead level, that'll give him that bad behavior we have. When I go to the community, he keeps screaming, cryin'. He doesn't like to wait for too long. That's why I worry about it (Participant # 12).

"He should not have to know what it's like to go and get your blood drawn every two months and then if somethin' wrong you go every week. He automatically walks into the doctors, holds his arm out, and says, "Boo-Boo. Which is not right, he is two" (Participant # 5).

Some caregivers described a physical reaction to knowing their child was sick or of a constant unrest and used LFS as a way to reassure themselves and give them some peace.

“We don’t feel good while they’re sick; we feel sick too. Well I feel sick” (Participant # 1R).

Interviewer: It helps to check in for LFS?

“Yeah it makes me feel better, that’s why if I could I’d go more, I would”

(Participant # 4).

Caregivers spoke of not being able to participate in activities that they felt were healthy and normal due to the lead poisoning of their child and the lead hazards in the environment.

“That means keep the windows closed, so that means no fresh air. We like to go out and play and we cannot do that as there is lead dust in the air and he cannot do anything and you just never know... (shrugs and laughs) (Participant # 2).

Caregivers describe how overwhelming the management of the lead hazards in the home could be and following up for LFS. This writer at times felt that at least three caregivers exhibited signs of depression.

Long term fear and anxiety, guilt and stigma.

The third dimension involves *long term fear and anxiety about the wellbeing of the child, guilt, and the stigma of lead*. Caregivers expressed the worry of losing the child they dreamed of, that the “normal” life for the child would not occur. This also included the wellbeing of the family and quality of life. Caregivers expressed guilt that their children were lead poisoned. Caregivers also shared that they felt a great deal of stigma, as a result of lead poisoning, and if social services had been called for failure to follow-up this contributed significantly to the

caregiver's feelings of stigma, guilt and shame. This dimension also included the worry of losing custody of children for noncompliance and/or not being able to lower the ELL. The properties of this dimension are watching, comparing, worrying and hoping. The third-dimension *long term fear and anxiety, guilt and stigma* as expressed by caregivers:

"There is going to be something wrong with her brain, she is gonna get the lead poisoning to go down or is it going to go up and she will have to deal with this for the rest of her life...so, that worries me a lot" (Participant # 1).

"I'm afraid if I can't get his lead down then in my mind he's going to die. There's gonna be something critically wrong with him. He'll lose a kidney, something will shut down, and I can't fix it, which is not good because I don't have the money to do anything about it. It sucks, it's horrible" (Participant # 5).

Other caregivers indicated that they felt overwhelmed not only by the news of lead poisoning and by the amount of information given to them:

"Frustrated ...because to get all this stuff they hand you and they keep handing it to you and you read ... and you re-read it and your re-read it and they keep telling you the same things...and what can you do.... (Participant # 2).

"It's too much information. Too much. Everybody has something to tell you, and I 'm tired of it. That's why" (Participant # 12).

"That is the problem. They give you a booklet in a packet and all this other stuff that explains it to you but some of us don't know medical terminology. Some of us don't

understand big words. If we wanna talk about it you can call somebody and they're always hurrying. They don't really go into detail and in depth about what you're supposed to do. I can sit there and read. I know I've had at least a thousand pages of information they've given me, pictures and everything else. I'm not illiterate. I can read it's just a little much" (Participant # 5).

Caregivers indicated that they felt frustrated with the amount of work managing lead hazards in their home and how nebulous lead hazards were to control. Caregivers expressed fear of living in a home with lead hazards.

"Constantly on top of everything he is around so it is just really frustrating (Participant # 2)

"I gotta go, I can't do this. They was just letting me know it where the lead was. It wasn't healthy for me and my kids, so it was like, I gotta go, so I did, I moved and I never looked back (Participant # 7).

Caregivers indicated that they felt that they were thought of as being dirty, as the focus of lead control, is cleaning and managing the dust that has lead hazards in it.

"It makes me think they think you're a dirty person or something and that's not the case" (Participant #9).

"It was embarrassing, yes. Another day, three trucks comin' in the morning. The whole day, I have to stay with my kids, at the library, to clean my house because of the lead. It was embarrassing. They put up a warning sign, 'This is a Danger Zone', Yes! Can you believe that? People are scare of me or something" (Participant #12).

Caregivers struggled with guilt and feeling that they were responsible for their child's lead poisoning.

"Makes you feel like you're not doing what you're supposed to, but I'm trying as much as I possibly can. Obviously not enough because they're still coming after me"
(Participant # 5).

"Thought it was my fault. I picked the house to move into and I was unaware of the lead. I wasn't aware that we were supposed to- when we moved in" (Participant # 7)

"Make me feel sad. That makes me feel like I'm irresponsible. I'm not a good mom"
(Participant # 12).

Caregiver's Coping

The second theoretical concept identified was *Caregiver's coping*. This represents what strategies caregivers used to not only address their child's ELL but to also calm their worries about the child's health status. For many caregivers these strategies were not developed in the beginning nor were most caregiver's able to fully understand or appreciate the significance of the child's lead poisoning and the interventions that they would need to use in order to control the lead hazards in their child's living environment. The core category: *Tells you if what you are doing is working* and core concept of *psychological reactions* both play a significant role in caregivers being able to develop the necessary coping strategies. Caregiver's coping has four dimensions 1) *doing*, 2) *vigilance*, 3) *knowledge*, and 4) *relationship/support*. *Caregiver Coping* was developed over time with continued experience, becoming familiar with the child's

behavior, the environment's lead hazards, and remaining in LFS, BLL results to gauge success of strategies and the knowledge that LFS provided.

Doing.

The first dimension is *doing*, essentially what caregivers described they did to address their child's ELL. Consistently every caregiver when asked to discuss what it was like to have a lead poisoned child and they would start to discuss the process of lead management and list all of the 'things' they did to control their child's lead level by managing the hazards in their home. In fact this was communicated with great detail and often stories about process of elimination were told about how sources of lead hazards were determined or never determined. Most caregivers spoke of the cleaning and managing lead hazards and child's exposure as a daily routine that was often constant. The *doing* is very much a part of LFS and essentially impacts on the outcome of the ELL.

"What I did to take control of it. I don't let him go everywhere, so I check the mother's house. I checked his grandma's house. Then once we narrowed it down, then his lead level was goin' down (Participant # 10).

You know if anything gets really dusty, then you dust everything because old houses can get dusty, you can dust one day and it can be dusty again the next day. I try to keep up with the housework like that" (Participant # 2).

The response to *doing* depended greatly on the wellbeing of the caregiver. The stress and process of LFS can take its toll. Some caregivers seem resigned to the outcome, others exhausted and unable to consider doing anything else.

Besides cleaning constantly, vacuuming, I wipe the walls down. They gave us step by step instructions, three bucket rule with spic and span.... I literally vacuumed the ceiling, I vacuumed the floor, I vacuumed upstairs where they sleep. I try to keep him on his diet as much as possible... we give him two different vitamins. ...We're hoping this will work. I've done pretty much as much as I possibly can, or that I feel that I can. I don't know what else to do (laughs) (Participant # 5).

"It's beneficial, but for me, doin' it every time, I have a headache and I'm tired. That's why (laughter)... I'm tired, too, because I don't know if I did anything in the house"
(Participant # 12).

Vigilance.

The second dimension, *vigilance* is the process caregivers go through assimilating all they have learned about lead from health providers and watching their child's behavior for any habits that would expose them to lead hazards. *Vigilance* is also watching and maintaining the child's environment in an effort to control lead hazards. Comparing and contrasting their child's behavior to look for changes. The underlying feeling during this process is one of fear and concern that that caregiver will find a positive finding.

"Yeah, we are watching him, watching him to make sure he doesn't get dust or anything in his mouth, watching him to make sure he does not get dust on his hands"
(Participant # 2).

"I keep watching him, from that time. I'm not letting him put anything in his mouth"
(Participant# 12).

Caregivers shared that vigilance was more than just watching for exposure but also watching the child for symptoms of lead poisoning and comparing what the caregiver saw to what they considered ‘normal’ would look like. Caregivers often spoke, when they were comparing, what they saw as symptoms in almost soothing phrases and diminishing the significance of any questionable finding to try to calm their own worries and anxieties. Often caregivers answered their own concerns.

“I still worry and wait...she...I still wait...so...I don’t know I just see what the progress goes with her activity and her hyperness and see where that goes” (Participant# 1)

“The one thing that I do watch for, the two times they (ELL) were high she had high fevers just like a viral infection but it was from her blood” (Participant # 4).

“His health is fine. I don’t know, if it was from the lead or if it was just his age, but he does seem to have a little bit of—I mean, he’s not bad, but he has a mild behavioral problem, sometimes. I’ve heard that lead can cause that. I don’t know if it that or just his age. Cause he learns a little slower than everybody else. Might be a hereditary thing his biological father learned slow too. I don’t know if it’s that or it the cause of the lead” (Participant # 9).

“Not showing any progression in his speech patterns or anything like that, then we’re going to go and get him tested and see if something’s mentally wrong with him. Here lately he’s kind of perked up a little bit. Thinkin’ he might be okay” (Participant #5).

Knowledge.

The third dimension is knowledge. Caregivers used knowledge to determine how to carry out the strategies they needed to successfully lower their child's ELL and manage the lead hazards in their home and determine how ill their child was.

“By applying the information they gave us, his lead level went down” (Participant # 10).

“The WIC office helped us. They told us lots of different things. Keepin’ the dust cleaned up. That lead came out of dust, out of buildings” (Participant # 13).

Some caregivers indicated they did not have enough knowledge to successfully mitigate the lead hazards.

“As far as people coming in and telling us what lead is and what it is not. The guy who came could not test for lead.... I wish someone could come in and do that for free... we have done alright for ourselves it has not gone above a 10... so obviously we are not perfect” (Participant # 2).

“More information about lead poisoning. That would be helpful so you know what is going on in your child's body” (Participant # 3).

Caregivers also indicated that having access to other caregivers with similar experiences would be helpful at dealing with lead poisoning.

“If I'm dealing with it right now and you tell me there is a meeting and all parent will be there, we will go. You meet other parents who are dealing with the same thing that you

are and discuss it. Then, because you're dealing with it right then you will do something, you know?" (Participant # 3).

For some caregivers not having the information impacted on their decision to engage in LFS.

This caregiver was undecided about whether it was that important. It was obvious that she had not understood the information given to her initially. This caregiver also felt it was not stressed how serious it was and later discovered she could be charged with medical neglect.

"They did give us some brochures which I only read one time. You know how it is. You read one time and put them aside. Just information so that I know what if going on in her body or is it normal or she has to come back and take it slow. Does it really help that much? Said she can check her when I go for her next appointment for her next shot, they will check her. That's how I see it, but how they can change to do that (medical neglect)" (Participant # 3).

Relationships, supports and barriers.

The fourth dimension is, *relationships, supports, and barriers*. Each caregiver indicated what supported them in staying in LFS and barriers that impeded their ability to be engaged. For most caregivers they needed a relationship and/or support to overcome the barriers. When caregivers spoke of facilitators remaining in the LFS process they often indicated they had partnerships with health care professionals (HCP) that appeared to be flexible, respectful, and the caregiver felt like an equal in the process. These HCP appeared to understand the culture of poverty and the challenges faced by these caregivers, recognized the need to be flexible,

appeared to be non-judgmental, and took the time to ensure the caregivers understood what was required to help the lead poisoned child.

“Yes, (name of lead nurse) she cares about me and (name of daughter) and I do not want to upset her and not go to my appointments” (Participant # 1).

Caregivers described needing other supports such as family to assist with the daily cleaning for lead hazard controls, transportation to and from LFS and financial and emotional support.

“I’m not the best cleaner but my dad-ya know he is here to help me out with a lotta stuff, cuz he has been through this. He helped me out the best he can and we just try to keep everything the best way we can keep it with five kids bein” around” (Participant # 11).

“Money is a situation for us, my parents help. If I need \$1.50 for the bus, I get there. Everyone once in a while they will take us or something-transportation is an issue, but when it comes to follow-up it is not an issue. I make it a priority” (Participant # 4).

One caregiver indicated it was his belief in God and prayer that assisted him to meet the needs of his grandson.

“I’m a praying man, and I pray for my grandchildren, and I believe in prayer, but also God to give us wisdom” (Participant #10).

For some caregivers the only support they have is the system and this is very challenging as the system rarely is dynamic enough to meet the needs of caregivers when needed.

“Now they are telling me change her diet. I don’t have money. I am really surviving. I’m going to a foodbank to get some food to bring home. I’m not going to be able to do

it. I can do that sometimes, but not the way it supposed to be for her not to fall back on it or for her to get well faster. Then if I cannot change that and I bring her and “Oh, the lead level is still high?” It’s not helping unless they change that from the source. Then help me change her diet. Widen the portions of the WIC. Give her more fruit at WIC. The one thing for \$6.00 is not helping her for a month or for the 3 months until I get her back there. It is really not helping” (Participant # 3).

“I quit my job and everything else to take care of the baby. It’s has been a struggle after struggle” (Participant # 13).

“Well it is like they send you to one place to another for one. They sent me to a referral for Children’s pediatric blood case management and all the way in another city. It’s a lot harder because I don’t have transportation now” (Participant # 14).

The one single event that consistently impacted on the therapeutic relationship of nurse and client was the threat of medical neglect or social services involvement because the caregiver was considered lost to follow-up or was being informed of the risk of not following up. The loss of this therapeutic relationship impacted not only on LFS engagement but how the caregiver viewed themselves as caregivers and their role and this was also cited as a source of shame and guilt and contributed to the stigma that caregivers felt having a lead poisoned child.

“Initially, when I spoke to the nurse to set up the appointment, for them to come to our home, I was told that if we didn’t comply, that they could turn us into social service for neglect and abuse of not following through with his blood work. I was astonished because he is my child. I’m a mother. I have three other children of course I am going to

comply, and take him to appointments, and make sure that he was taken care of....Maybe it was just a way of stressing how important it was for (child name) to be seen. I think there is another way for them to go around it instead of—I felt like I was being attacked” (Participant # 6).

“The WIC office got a hold of me, and said if you don’t get this done-threatened me with child-social services. I said “Ma’am it’s been done through my doctor’s office” (Participant # 13).

“Then I wouldn’t go back to the Health Department. I wouldn’t. I’ll take him elsewhere, anywhere, to avoid them, which I think is kinda of rude of them to do the things that they do and how they go about their little procedures” (Participant # 7).

Meeting Expectations

The first and second theoretical concepts of *Psychological Reactions and Parental Coping*, create the conditions for the third theoretical concept *Meeting Expectations*. *Meeting Expectations* is the caregiver participating in LFS and being successful in addressing lead hazards in their child’s living environment. *Meeting expectations* has two dimensions, 1) *caregiver role and social expectations* and 2) *health care and system expectations*. These two dimensions were very strong deciding factors on whether caregivers remained in the LFS. These two factors were present with any caregiver who remain in LFS.

Caregivers expressed expectations for themselves that they would meet the needs of their child. Caregivers described their role in addressing their child’s lead poisoning as an obligation or responsibility that was ‘just’ understood. Although they did not discuss social norms they

alluded to this with phrases such as ‘flesh and blood’ or ‘spiritual obligation’. *Meeting Expectations* included the health care system expectations as well and what caregivers expected from health care providers, the support they thought the system would provide, expectations caregivers had of health professionals, and the expectations demanded of them.

Caregivers had expectations about what kind of care was most appropriate for their child and appeared to weigh these considerations in determining where they would go for LFS. Part of the decision on where to seek LFS was dependent on the provider’s understanding of their child’s lead condition, the ability to explain information, and treat them with respect. In many instances caregivers arranged to follow up with Children’s Hospital even though the WIC could be combined with LFS and was often within walking distance.

Caregiver role and social expectations.

The first dimension *caregiver role and social expectations*, caregivers identified their role as protectors and advocates and it was a role or responsibility that was theirs alone that was placed on them by society because it was their child. They saw addressing their child’s lead poisoning as their obligation.

*“It’s my job as his grandfather to take care of him. That’s my son’s kid
(Participant # 10).*

“She really can’t make those decisions on herself. It’s your responsibility. If your baby is sick, you got to be with her. That’s your responsibility. I don’t think it’s a role, and I don’t think it’s a job, cuz you did had her so it’s your responsibility. It is like some kinda spiritual obligation” (Participant # 1R).

Caregivers discussed acting as advocates for themselves and their children in regards to LFS protocols:

“The problem was communication, not from my part. I was just waitin’ for the results and never heard anything. We called her doctor after WIC threatened us. Since then they have been pretty much on top of it. Because I done told ‘em, I can straighten this up real quick. We can get an attorney and get this straightened up real fast. That upset me. If I’m doing somethin’ to hurt her, I can see that, but we’ve done our part”

(Participant #13).

“I just got his lead checked at the doctor I am not going to turn around and get it checked at the WIC office. I will get a copy of the lead and show them I am not going to let them stick him twice” (Participant # 7).

Many caregivers described the barriers that often impacted on remaining in LFS. For many caregivers they did not return and were considered LFU. This often resulted in the caregiver not returning to that particular clinic for LFS as they were reported for Medical Neglect. In this region there are other options for LFS however if this had not been the case this would have been an access issue.

“I missed a couple of appointments. Then, she called and she told me, you know, I explained it to her. I be like I understand. I’m doing the best I can, I said but walking with two kids from one city to another is really hard especially when you’re the only one doing it” (Participant # 8).

“He misses school because his doctor, he is only there on Tuesday at 2:00 p.m.

(Participant # 12).

Caregivers were asked about the role of the community in assisting with lead poisoning.

Consistently caregivers saw addressing their child’s lead poisoning as a caregiver role and responsibility.

“I really don’t know cuz...me talkin’ about my personal life or what my daughter go, nah, I don’t talk to my neighbors about that. Now, do talk to my mom and her daddy about him having lead poisoning, but me talkin’ to my community” (Participant 1R).

Caregivers indicated that there were often so many expectations that they had to prioritize what they were able to handle even if it meant opting to not return for WIC appointments and attending LFS or not wanting to duplicate appointments so would go to Children’s Hospital for screening as well.

“Yeah. I was getting WIC and then I just quit. It was just too much” (Participant # 11).

Healthcare and system expectations.

The second dimension is *health care and system expectations*. Many caregivers had perceptions of the role that the health care system would play in assisting their child with lead poisoning. Caregivers spoke of wanting a more caregiver friendly approach to LFS:

“I wish they would work with me. I can’t chose what they need to do. I just wish they would be a lot more understanding about it. If I don’t make an appointment right away

they make it for me. I don't have the choice to choose time or date, because they do it (Participant# 5).

Caregivers felt that they were held to standards to not miss appointments and manage lead hazards in their houses to lower their child's ELL however they felt the same standards were not held to health professionals.

"She put our blood somewhere it was not suppose to go. They're callin' me back like, well you have to go back" (Participant #8).

"Can I bring him back a separate day, because I don't want his lead checked the same time as his WIC visit with the rest of my kids? They said no. Then we get there and they make us sit for numerous hours for WIC and we still have to get lead tested. It could be more efficient for parents" (Participant # 7).

"If they put someone else on his case who has no clue about it, and they test him, they open up a new folder, and I'm like, I already have all of this. You have to explain to a professional about your situation. I don't think that is right" (Participant# 5).

When asked about the choices they made in lead case management and LFS screening many caregivers indicated the choices they made were around scheduling appointments.

"Basically, it's fitting it into my schedule. I can make the appointments and stuff like that work for me a little better. Yeah." (Participant #14).

With time many caregivers came to better understand their role in LFS but this confusion did result in some of the emotional reactions, discord between health professionals working in the system and caregivers, and the risk for involving social services.

“My biggest concern was them takin’ him from me truthfully...oh, he has high lead levels. They gonna take my kids from me” (Participant # 7).

“I received another letter: “If you don’t bring child, we goin’ to sue you because its neglect” (Participant # 12).

Caregivers had concerns about the larger system itself as caregivers were required to follow protocols and yet lead safe work practices were not enforced when contractors were renovating in their neighborhoods. A caregivers also discussed that historic codes had to followed in neighborhood and those codes were more important than his child’s health.

“In our neighborhood they has done some construction work. It started approximately 4 years ago. That’s when (child’s name) starting having high level. The neighborhood has higher levels of dust, lead in the dust, which was the main thing in our home was the dust” (Participant # 6).

“I have done a lot of contracting work on a lot of these houses around here, for historic houses, and I knew about the historic codes but I did not know about the lead thing....they are supposed to know around these houses what they are supposed to do with the lead but they don’t all their doing is gutting them out” (Participant # 2).

A caregiver who was empowered and advocated for herself and her child indicated that she got push back from health professionals when she requested for LFS during a WIC appointment. Education and using the system guidelines along with relationships supports of her pediatrician allowed this caregiver to fulfill her perceived role.

“ I was upset because I know I can ask, and they (WIC) told me no, in November, when I made her doctor’s appointment for her four year her pediatrician told me I was allowed to have it. They did her blood- the arm stick it was 6.4. Then I go really angry.....I go every three months for her WIC, so he said that it is my duty that I can ask for her to be tested every- because it has been elevated, so I feel better what I’m doing as a mother. (Participant # 4).

Case Management Chart Review Findings

During each interview the caregiver’s permission was obtained to conduct a chart review on the lead follow up case management. Of the participants 79% still had open cases and 93% had received a case management home visit. Fifty seven percent had been in LFS case management 4-53 weeks, 43% had been in LFS case management for 88-157 weeks. On average each caregiver had received at least 3 follow up phone calls with the largest number being 10 phone calls, 93% had case management home visits, 36% had environmental risk assessments completed in their homes. The number of clinical visits for LFS ranged from 0 to 6, with the number of BLL retests ranging from 2-13 blood draws. Sixty four percent of the participants missed appointments and the number of appointments ranged from 1-6, 57% received calls for failure to return for follow-up. Two of the participants were lost follow-up and

were re-connected through Family Cabinet Services under medical neglect provision. See appendix H for all the data collected in the chart review.

This chapter presented the findings of a grounded theory study on caregiver's decision making process in remaining in LFS. The aspects of this process as described by caregivers was *Psychological reactions*, *Parental Coping* and *Meeting Expectations*. These patterns were not in stages but a cyclic process with each process being weighed over and over to determine benefit of returning for LFS at that time. Most caregivers indicated their intention was not to never return LFS but a balance of the priorities at that time. The in-vivo core concept, *Tells you if what you are doing is working* is how participants viewed this process and they used LFS to meet their child's health needs as it pertains to an ELL.

Who, What, When, Where and How

Using a constructivist approach means looking at not only how individuals perceive their situation but also why they construct the meanings and actions they do. An extension of this is learning how, when and to what extent the participant's experiences are found in the larger networks, situations and relationships (Charmaz, 2006). "Analysis are contextually situated in time, place, culture and situation" Charmaz, 2006, p. 121). Corbin and Strauss (2008) also indicate that theory would be incomplete without the features of who, what, when, where and how.

In this work the *what* and the *how* are reflected in the key concepts, Psychological reactions, Parental coping and Meeting expectations. These concepts are situated in the caregiver's social views, societal expectations of caring for the child, as well as the statutes and policies that structure the lead program and society's expectations about what the caregiver role and responsibilities are for a child with ELL. Managing the LFS processes is very much

influenced by the culture of poverty as disadvantaged families are more likely to be at risk for lead exposure. *Where* is identified by anywhere that lead hazards exist and need to be managed. This could be the child's home, another location or the surrounding community itself. Again the *where* is also situated in social concepts as many caregivers will tell you all the houses in their communities have lead in them another illustration of the culture of poverty impacting on this concept. Policies provide legal access to family's homes by the Health Department statutes control the management lead hazards, however as noted by caregivers this is dependent on whether these laws are enforced or not. *Where* lead hazards were found was often nebulous, as many caregivers did not have their homes tested so were unsure of the location of lead hazards. The nebulousness of lead hazards gave rise to the in-vivo core concept, *Tells you if what you are doing is working*. Caregivers indicated they used the results of LFS to determine how accurate they were at the identification of interventions and location of lead hazards. Lead testing of the home was dependent on the BLL of the child. During this study there was a discrepancy between the action on BLL for case management and lead testing of the home. This meant for some families their homes were never tested.

Participants viewed the role of managing LFS for their child as their role and obligation. Caregivers discussed a collaboration with health professionals and were most successful at addressing the lead hazards when an ongoing relationship had been developed. The participants indicated that the health professional held a special role with important knowledge and often facilitated the process in order to assist the caregiver. Participants saw the competency of the health provider as very important. If this was in question caregivers often doubted if the health provider was credible or not. One area that proved to be a barrier to collaborative relationship between caregiver and health professional was the use of Medical Neglect in any form.

Participants also used other relationships with family to assist them in the LFS process (see appendix I).

This chapter presented the findings of a grounded theory study of caregiver's decision making process in remaining engaged in a lead follow-up program with a child with an elevated blood lead level. The participants described concepts of Psychological reactions, Parental Coping, and Meeting Expectations as the process to remain in lead follow-up program. This process was not static but cyclic and continuous throughout the entire case management process. The in-vivo core concept of *Tells you if what you are doing is working* was used as a way of judging whether what the caregiver was doing was successful at lowering their child's ELL.

Chapter Five: Discussion

Caregivers of lead poisoned children play a very important role in LFS. Caregivers are the access point for LFS and need to maintain and control the lead hazards in their child's living environment. Grounded theory method was used to better understand the caregiver's decision making process to remain in LFS. Three HD lead clinics were used and 15 interviews were conducted with 16 participants who had children with ELL and were enrolled in LFS and had a least two screenings. Data was collected using theoretical sampling and analyzed using constant comparative by the use of written memos (Chamaz, 2014).

This work developed a core category and three associated concepts that reflected the caregiver's descriptions of decision making processes and context for remaining in LFS. The core concept of, *Tells you if what you are doing is working* describes how caregivers view LFS. *Psychological reactions*, *Caregiver coping* are the processes used by caregivers and can act as facilitators or barriers in the caregiver *Meeting expectations*. See Figure 8

Discussion of the Findings

There are three crucial points in the findings. The first is that *Psychological reactions*, *Caregiver coping*, and *Meeting expectations* were described as the process for decision making in LFS. Each of these was not static, nor did they often occur in order, but were cyclic and part of the process in varying degrees at different times. The second point, participants described the care of their children with ELL, with a level of oversight that often compares too many pediatric chronic illnesses. The third point, all of the participants and their families, who choose to report their household income, met the 2015 poverty threshold guidelines (HHS, 2015). The latter two points are woven throughout the discussion of the concepts as conditions and consequences that

impacted caregivers in *Meeting expectations* and will also be discussed in terms of implications for practice, education and research.

Chronicity of lead poisoning.

Chronic illness refers to the lived experience of a long term bodily disruption or health and often is a result of living with a chronic disease. Chronic illnesses are often overlooked as it does not fit in with the medical or administrative model. Chronic disease and illness are both greatly impacted by socioeconomic status, education, employment and the environment thus when looking at this phenomenon it stands to reason that the least advantaged will experience the most significant disparities in health outcomes (Martin, 2007).

Lead poisoning is often not fully understood as a chronic illness. However it often requires the same level of commitment and management as chronic illnesses such as asthmas and type 1 diabetes in children. Although the symptoms are usually less acute and less imminently fatal, the long term effects can have a long life impact with significant cognitive impairment and academic success for a child. An elevated lead level is treated through the modification of the child's environment to mitigate exposure to lead, which includes a rigorous daily cleaning schedule, improving nutritional status services such as speech and behavioral therapy to impact on any growth and developmental needs as quickly as possible. The case management process requires following up for blood work, ongoing education and support for the caregiver who coordinates and carries out the majority of these activities. For some families LFS can be a weekly or monthly visit along with doctor's appointments, home inspections and environmental assessments. This also does not include the day to day requirements such as dusting, cleaning and mopping and using lead safe practices which must continue as long as the family lives in the home or the lead source is abated. Caregivers experiencing ELL are compared to other

caregivers with children who experience significant chronic diseases such as asthma, diabetes or cancer, one would not expect the experiences to be similar. However many of the experiences and comments made by both groups of caregivers are similar. Throughout the discussion comparisons will illustrate how similar the experiences are.

Psychological reactions.

Psychological reactions were experienced by caregivers throughout the treatment process for their child with ELL. *Psychological reactions* impacted significantly on caregiver's wellbeing and peace of mind. This concept included three dimensions: *discovery, psychological involvement, and long term fear and anxiety, guilt, and stigma*. Caregivers expressed fear and worry about their child being lead poisoned. Caregivers described significant reactions to learning about the diagnosis, attending the LFS appointments for repeated blood draws, watching their child's discomfort and managing their child's reactions to these visits. Caregivers indicated they were sad that their child was lead poisoned and that this was not what they wanted for their child. Many described the loss of the healthy child they thought they would have and also the quality of life for themselves and their families. Some of the participants displayed symptoms that could be seen as potentially being clinically depressed.

Parents with children diagnosed with a chronic condition experience multiple losses. The loss of a healthy child, freedom, confidence in being able to care for their child, spontaneity, and disruption to the family's daily life. These losses are considered normal, feeling sad and depressed are also common responses and yet many parents are not aware of this nor are they informed (Lowe & Lyne, 2000; Northington, 2000). Most caregivers move on, however recurrent bouts of sadness are normal that often result from internal and external triggers. It is important for caregivers to care for themselves (Northington, 2000).

Ekim and Ocakci (2016) conducted a review of 22 research studies that assessed for caregiver burden in caring for children with asthma. In this review stressors were identified as caregiving activities, such as preventing symptoms, intervening to symptoms, financial burdens, parental responsibilities and personal distress. Factors identified as contributing to stress included income status, marital status, and caregiver child relationship. Caregivers who identified as having high levels of daily stress had risk factors such as unemployment, low income, neighborhood safety, exposure to community violence exposure, and daily caregiver asthma responsibilities. These risk factors were also associated with a lower level of quality of life by caregivers (Ekim & Ocakci, 2016).

Caregivers seem to struggle with being able to manage all of the logistics of their child's LFS. They also often appeared to make poor decisions or no decisions at all. When asked what decisions they made about their child's lead poisoning management they mostly answered, that they were able to choose the appointments times. It appeared that many of the caregivers played less than an active role in their child's LFS. Decisions to engage or remain in LFS seem to result in role expectations or the threat of medical neglect. Many of the caregivers' spoke of feeling obligated, others spoke of feeling concerned they would lose their children if they were not able to lower the ELL.

Waggoner, Adams, Muchant, Wilson and Hogan, (2008) carried out a study to assess illness severity and its relation to psychosocial factors in children with primary immunodeficiency disorders (PID) and kidney disease. A secondary goal was to assess families' use of physician for psychosocial support. Sixty four caregiver-youth dyads (age 8-20 years) were in the study and were categorized as mild, moderate, and severely ill and compared with a healthy group. Instruments were used to measure illness severity, adult coping behaviors,

child and adolescent coping behaviors, and behavioral assessment scale for children. Children in the mildly ill group were reported to internalize more and have maladaptive behavior when compared to the moderately, severely ill, or healthy groups. Caregivers of the mildly ill group also reported more maladaptive behaviors than the other three groups. Physicians reported that the caregivers in the mildly ill group appeared to engage in denial surrounding the disease and treatment process. This was most likely due to the lack of symptoms and the appearance that their children were healthy (Waggoner, Adams, Muchant, Wilson & Hogan, 2008).

Other worries expressed by caregivers were not just about the present but the unknown long term impact on their child's health. Even when caregivers were carrying out the activities to mitigate lead hazards and monitoring the child's behaviors they spoke about watching, worrying, and being ever vigilant. The often unknown sources of lead hazards in the living environment added to their stress, worry, and need for a high level of watchfulness. Caregivers expressed that they thought they had done everything to control their child's exposure only to discover the BLL had increased. Other caregivers also shared there were times they considered lead poisoning to be the invisible disease as their child looked healthy and normal so they considered not returning for LFS.

Lipstien, Brinkman and Britto (2012) carried out a narrative review of current research on parent decision making about pediatric treatments. The review found 55 articles with 52 of the studies descriptive or qualitative. The findings indicated that parent's decision making was impacted by emotional factors such as worry, stress and decisional regret and poor decision making which had a significant impact on negative decision outcomes. Other studies also found familial and emotional factors had more of a significant impact than recommendations from a physician. Studies conducted in the clinical setting determined parent's decisions were

significantly impacted by emotions, beliefs and values as well (Lipstien, Brinkman & Britto, 2012).

Caregivers also indicated they experienced guilt because their children were poisoned, they had failed to protect them, and felt stigmatized having a child with lead poisoning. Lipstien, Brinkman and Britt, (2012) review found a common theme that parents with chronically ill children felt guilt, and believed they had failed as a parents. The feeling of guilt also impacted on the caregiver's ability to make decisions. Parent's decision making can also be influenced by their faith, beliefs such as 'not giving up' or the social acceptance of a treatment (Lipstien, Brinkman & Britt, 2012).

Caregivers described that because lead hazards were so closely tied to dust and cleaning they felt it inferred they were 'dirty'. A literature review was undertaken to gain a better understanding of factors of caregiver's decisions to attend LFS (Boreland & Lyle, 2007). In that review 34 articles were published on blood lead screening rates, seven of these articles dealt with caregiver's attitudes on lead screening. There were no articles that considered lead follow-up screening. The barriers that these authors identified in the literature were: 1) not recognizing the problem; 2) thinking nothing can be done about the problem; 3) fear of the disease itself, the screening procedure, or the consequences of testing; 4) fear of stigma or broader cultural barriers; 5) practical difficulty in accessing services; and 6) health professional attitudes. Many of the concerns and barriers found in the literature review were also consistent for screening of other children and adult health concerns (Borland & Lyle, 2007).

Caregivers who ended up interfacing with Social Services also experienced anger and shame and reported significant negative reactions. Their negative reaction usually destroyed the therapeutic relationship between the lead case manager and/or the lead nurse and the caregiver.

As a result the caregiver often did not return to the clinic they were receiving care in at the time of the LFU report. In the region this research was conducted there is a large Children's Hospital so that care for lead poisoning could be accessed there. In smaller regions this might not be an option and transportation was identified as a major barrier when attending the lead clinic in the Children's Hospital thus leading to access issues. Howego et al. (2013) reviewed the literature to determine the benefits of positive therapeutic alliances with clients who required long-term care and case management. Although the search resulted in sparse findings, studies that were found indicated that a therapeutic alliance were very beneficial to the treatment outcome (Howego, 2013).

Children with ELL often have symptoms such as hyperactivity, sleep, and learning issues. Caregivers also discussed the stress of managing their children especially in the community, trying to get enough rest and the long term impact on their child's future. During the interview process this researcher noted that at least three of the participant's children exhibited symptoms of hyperactivity and speech delays. These same caregivers also exhibited and described symptoms that were common with depression. Waggoner, Adams, Muchant, Wilson and Hogan, (2008) in their study reported greater use of physicians for psychosocial support by caregivers with children with chronic illness, (75%-100%) versus the healthy comparison group of 44%.

Childhood illness in a family can result in significant stress for all members. It often heralds a change in family roles, relationships and disrupts family normalcy. After diagnosis, caregivers start to experience the longevity and difficulty of managing medication adherence, procedures, surgery recovery, doctor or hospital or clinic visits, and 'normal' family functioning such as household duties, homework, social activities (Bouma & Schweitzer, 1990: Williams,

1997). For children with lead poisoning they most likely will not be hospitalized or have surgery but frequent clinical visits, blood draws and the daily routine of maintaining the lead safe cleaning to manage lead hazards in the child's environment is burdensome.

Caregiver coping.

For this caregiver group being able to engage in *Caregiver Coping* at times was very challenging. The fact that these caregiver's income is well below the poverty line, they live in underserved, congested neighborhoods, and the majority only have a high school or education or lower. This puts the group at a significant disadvantage for *caregiver coping*. Many of the caregivers struggled with health literacy and understanding the information given to them. These caregivers appeared to lack emotionally and financially support. Marhefka et al. (2006), examined caregiver psychosocial correlates and children's adherence to antiretroviral therapy (ART) in a cross sectional descriptive design study. The results showed that parents with greater levels of psychological distress were more likely to have children with low ART adherence. Parents with higher incomes had higher ART adherence. In the study many of the participants lived in impoverished neighborhoods, had difficulty maintaining stable living environments, home lives were chaotic and unstructured so the routine of medication adherence on a long term basis was very challenging. Life for these families were short-term goal focused, on feeding the family, avoiding harm, and stable housing (Marhefka et al., 2006).

When caregivers were asked to discuss lead poisoning they would list off the necessary knowledge and tasks that are considered or carried out daily in order to lower their child's ELL. This was the *doing* portion of the process to parent coping and the reframing of the caregiver role to incorporate the new knowledge and activities on how best to manage their child's ELL, and the mastering of treatment. The other portion of this process is *vigilance* of the monitoring

portion of treatment. *Vigilance* is the observation of the living environment and their child's condition. Again this is a process was an accumulation of experience through observation, seeking knowledge, and returning for LFS to determine if *what you were doing was working or not*. This researcher questioned if perhaps *vigilance*, although important to the well-being of the child, contributed to caregiver's anxiety and worry and decreased their ability to carry out the necessary treatment regimen for lead management of their child.

McCann (2015), describes vigilance as a continuous partial attention (CPA), a state where most of the attention is on a primary task but one is also monitoring several other background tasks (McFredries, 2006). This has also been phrased as the 'always on' mentality (Stone, 2008 as cited in McCann, 2015). Many are familiar with this as it relates to work, e-mail and other responsibilities, however for children with complex needs this is different. Vigilance tasks have been found to be resource demanding, capacity draining and linked with significant stress (Warm et al. 2008). There has been found a significant correlation between the duration of caregiving stress and cellular aging independent of maternal age (Epel et al. 2004). The difference for caregivers with children with complex needs is always need to be in a state of readiness and children cannot be turned off so there is little respite. Parents of children with complex needs often describe being at the breaking point (Doig et al. 2009).

For some caregivers they were empowered and embraced the role they could fulfill. The role of providing for and protecting their child. Mu (2006) found that a sense of mastery in being able to manage the child's illness results in the formation of parental coping. For other caregivers it appeared that the challenge of *doing* and not being successful at mitigating the source of lead was demoralizing and contributed to caregiver burden and burnout. Bolyai, Sadler, Knafl, and Gilliss (2003) in a literature review looked at caregivers whose children had been diagnosed

recently and new to the process and found these caregivers were most likely to struggle with *caregiver coping*. Fear and anxiety seemed to prevail and knowledge often had yet to be internalized.

When some caregivers spoke of the minimizing the lead hazards in their homes or attending LFS they sounded ritualistic and ‘hedging their bets’. In other words they did not appear to understand how lead control and LFS worked but did not want to risk dropping out or were afraid of the consequences such as medical neglect. Sokolova and Smith (2015) conducted a literature review on factors that contributed to poor treatment outcomes in childhood atopic dermatitis. The finding indicated that many caregivers found the treatment regimens to be complex and burdensome related to frequency of applications, the long term therapy, and the multiple medications. Lack of knowledge was another theme that resulted in incorrect applications or confusion which directly impacted on treatment adherence and outcome. Impaired quality of life was a significant issue for caregivers and resulted in a decrease in adherence (Sokolova & Smith, 2015).

The Health Literacy of Parents in the United States: A Nationally Representative Study found that parents with less than high school were greater than 8 times the odds of being categorized as low health literacy. The findings indicated that almost 70% of parents had difficulty with health insurance forms, and 59.2% had difficulty understanding over the counter medication. The study found 1 in 4 parents had limited health literacy skills and only 1 and 7 parents were considered proficient. Parent health literacy appears to be linked to their child’s health outcomes (Yin et al. 2009). In order for caregivers to carry out the lead hazard control and remain in LFS, caregivers must be able to make decisions about the management of their child’s treatment for lead. For many caregivers when asked about this indicated they did what

they were told to or made decisions about timing of appointments. The two caregivers who were empowered to manage their child's lead poisoning were in the higher income levels, had college or some college education, had significant family and emotional support, and had experience with the healthcare system as they personally had medical insurance and understood the system.

Lipstein et al. (2012) found that parent's ability to make decisions was impacted by many factors. Prior experience, another family member's experience, other influences such as doctors, school staff, community members, helped to increase understanding of the disease process.

Rodgers and Hawks, indicated that empowerment is demonstrated by the ability of the caregiver to problem solve and improve decision making (as cited in Panicker, 2013). Panicker, found that the stage of a child's illness impacts on parental readiness to care. Caregivers who are in the early stage of the diagnosis are often still in shock or denial and are not ready to be empowered. Parents need to understand and accept the child's illness to actively involve themselves in care and is a prerequisite for empowerment. Empowerment was also noted to improve parental coping (Panicker, 2013). Both of the participants in this study who illustrated empowerment also discussed that they had to advocate strongly with health professionals to receive the care they felt their child needed. They indicated that they received significant push back from health professionals. Panicker (2013) study found that health professionals raised concerns about the negative impact of empowerment and felt that parent misused system supports, or took over the care of their child completely. The writer did indicate they felt this was a reaction to the disempowering behavior of the professional rather than the negative effects of parent empowerment (Panicker 2013).

Caregivers were most successful at LFS when they had a significant support or relationship to help them navigate the barriers. Caregivers indicated at least one significant

family relationship or health professional that they relied upon to leverage support for them. One of the biggest barriers to accessing LFS was transportation and because these caregivers were disadvantaged they had to rely on others. Caregiver resilience and coping is improved when caregiver's receive support in important relationships with family (Mu, 2006). Some caregivers spoke of the emotional support they received and encouragement that allowed them to make the necessary changes such as move. Another family were able to purchase a lead safe house because they lived with family members for months. Factors that can impact parental coping include: 1) family conflict, 2) parental relationship changes, 3) parental communication difficulties, 4) financial concerns, 5) recent family death and 6) perceive caregiver role strain (Melnik & feunstein, 2001). Sigurdardottir, Garwick, and Svavarsdottir, (2016) undertook a cross-sectional study on perceived family support, family quality of life, and expressive family functioning on 177 families who had children hospitalized with chronic illnesses. Perceived family support was a factor that was able to predict both the mothers' and fathers' satisfaction with healthcare services for their children. The importance of support for parents through information resources, family health promotion activities, and emotional support was essential for caregivers to be able to carry out caregiver activities on a daily basis for their children (Sigurdardottir, Garwick, & Svavarsdottir, 2016).

Other caregiver's spoke of the relationship they had with the lead case manager or the lead nurse in assisting them to successfully navigate LFS. These alliances allowed caregivers to work around barriers such as transportation, standing orders for blood draws at labs, and accommodation with appointments. Working with the same lead nurse or case manager developed alliances which helped caregiver coping. Not every caregiver had these established alliances.

Many of the caregivers spoke of their interest in attending support groups for caregivers with lead poisoned children. Lead poisoning can be very isolating and the lead control activities are mostly carried out in the home in isolation. Caregivers do not know how successful they have been until they return and received the LFS results. Caregivers also indicated they did not share the status of their child with others in their communities. Water et al. (2017) carried out focus groups of parents caring for children with asthma. The findings indicated caregivers preferred face to face support group meetings with other caregivers experiencing the same issues. Parents indicated in the study that they were able to gain social supports and also information on how to manage their child's asthma. These venues over time provided emotional support and the building of relationships (Water et al. 2017).

Core Category: Tells You if What You Are Doing is Working

An elevated lead level is treated through the modification of the child's environment to mitigate exposure to lead, which includes a rigorous daily cleaning schedule, improving nutritional status and mitigate any physiological and growth and developmental needs as quickly as possible. The case management process requires following up for blood work and ongoing education and support to the parent for all the activities required to ensure the ELL continues to come down. For some families LFS can be a monthly visit along with doctor's appointments, home inspections and environmental assessments and this does not include the day to day requirements such as dusting, cleaning and mopping using lead safe practices which must continue as long as the family lives in the home or the lead source is abated. When caregivers experiencing ELL are compared to other caregivers with children who have experience significant chronic diseases such asthma, diabetes or cancer, one would not expect the

experiences to be similar. However many of the comments made by both groups of caregivers are very similar. This indicates that lead poisoning has many of the features of chronic disease management.

The phrase, *Tells you if What You Are Doing is working*, was used to describe the value of LFS and why the caregivers continued to go even when they discussed their dislike of the LFS process and did not appear to be engaged. Lead follow up screening helped many caregivers determine if the activities that were undertaking impacted on the child's environment and reduced the lead exposure. Many caregivers shared that trying to determine where the source of lead was and how the child was being exposed was very frustrating. Caregivers adopted many practices, however they did not know how effective the practices were until the child was tested the next time. In the State of Kentucky statute LFS is mandated when there is an ELL. Some caregivers did not understand this or did not see the value of this activity. For some caregivers once informed of the need to attend and were given more information including the risk of being charged with medical neglect the caregivers started attending LFS. Many caregivers describe LFS as being very frustrating due to the frequency and the nature of the reaction of the child to the blood draw. Caregivers described it as very traumatizing for the child and often themselves as well. When asked if they intended on attending, caregivers cited that it is essential to understanding how they are impacting on the lead hazards.

Meeting Expectations

Meeting expectations was achieved when the caregiver was able to manage lead hazards in their child's environment and remain in LFS. Caregivers did not necessarily become engaged in the LFS and case management as they were required to attend LFS and lower their child's

ELL or face being charged with medical neglect and potentially losing custody of their children. Therefore this concept is more about, *meeting expectations* versus being engaged in the process. High risk families are very vulnerable, with the characteristics of learned helplessness, powerlessness and lack of resources. This can threaten the welling being and health status of their children (Schorr, 1988). Public health nurses are considered experts at managing many of vulnerable families and use the practice of both empowerment and coercion to ensure the wellbeing of vulnerable families (Zerwekh, 1992). Certainly this is seen in this research, as the standard practice for managing caregivers with children with ELL. Many of the participants were informed of the risk of becoming LFU. Thus when participants were interviewed they were often critical of the process of LFS and case management but they either indicated they continued to attend because of the role expectation of being the child's caregiver or the expectation by the system that if they did not, they would be charged with medical neglect and lose custody of their children. This process significantly impacted on the psychological reactions of caregivers and added to their worry of lowering their child's ELL. Caregivers also started to internalize the strategies to manage lead hazards and use LFS to gauge their success. Family caregiving has many competencies that are required by the nurse however sometimes the competencies needed to be use in public health are: "persuading parents to change high risk behaviors toward their children and saving children if the risk continues" (Zerwekh, 1992, p. 101). This dichotomous role for public health nurses impacts greatly on the system. "The result is a system which is fully effective neither in preventing maltreatment nor in respecting family privacy, but which lurches between two poles" (Dingwall, et al. as cited in Zerwekh, 1992). Although the importance of the child's wellbeing is certainly important in the role of the public health nurse, enforcing LFS via medical neglect impacted the therapeutic relationship in this

study. Therapeutic relationships “is a dynamic, two way, reciprocal relationship between caregiver and at times the patient’s family” (McKlindon & Barnsteiner as cited in Ramja, 2014, p. 496). Ramjan (2004), conducted a naturalistic inquiry with 10 Registered Nurses who worked with adolescents with acute anorexia nervosa. Nurses reported because the treatment regimen required significant structure it was followed and enforced it even if the nurses were not convinced of its value. The power struggle resulted in the mistrust of both nurses and patients. The nurses unconsciously became jailers and enforcers. As a result there was a power struggle that resulted in a loss of alliances between the nurse and the patient. In order to be discharged the patient had to follow the program so essentially they had no control and more importantly a lack of therapeutic alliance to assist with their recovery (Ramjan, 2004).

Caregivers in this study found reasons to remain in LFS and case management. For both caregivers this reasoning was both social constructs that required a level of behavior from the caregiver. Whether that be the caregiver role and obligation or the system’s expectation that caregivers will not place their children at risk or lose custody. Unfortunately this did not foster engagement although with time and repeated attendance to LFS and case management most caregivers were able to lower their child’s ELL

Figure 8 is a descriptive overview of the beginning of a substantive theory. The diagram demonstrates a reciprocal cyclic relationship and does not allow for the falsification of any of the findings. The next step in this research is to test this theory, with directional findings to determine what concepts are essential or could be falsified.

Lead poisoning is a significant health issue as well as a social justice issue that is embedded in multiple communities throughout the U.S. At the **macro level** the landlord does not seem to be accountable for management of lead hazards and cleaning up the property that is the

result of the child's illness. Families are paying money to live in the very homes that are lead poisoning their children and landlords are realizing a profit from this relationship. There are statutes which oversee lead in rental property but caregivers certainly were not aware of them and did not seem to see the role that landlords played in this situation. Caregivers seemed to be held fully accountable for the management of the living environment. The policy for the initiating of case management is 5 µg/dL and an environmental assessment of the home is at the level of 15µg/dL. So until the child BLL increases to the actionable level of for environmental assessment the caregiver is required to make an educated guess about where the lead hazards are in the home. This uncertainty places the child in physical harm and both of these interventions should be actionable at the level. This does not seem like good practice if we are truly committed to the prevention of lead poisoning and care about the health and wellbeing of our youngest citizens.

At the **meso level** the system appears to be set up to serve the system and the process versus the client. The priority is accommodating the systems work flow versus being client centered and collaborative. The caregiver is required to meet all the appointments, manage all lead hazards in the home, and lower their child's ELL. There does not seem to be any recognition that these are disadvantaged families without resources. The practice as it stands now is oppressive and would be traumatic for any family to experience. Better recognition of the burden and chronicity that lead poisoning places on caregivers is essential. Resources and supports that help to assist families in addressing this health concern are essential.

At the **micro level** the caregivers appear to shoulder most of the blame for their child's lead poisoning. Not only do caregiver's they blame themselves but the overarching theme of stigma is felt from health professionals and the communities in which they live. This also has an

impact on the therapeutic alliance that should be established to assist families and an overall mistrust of the very system that is established to help. These families live in communities that are often not safe and are violent. From the significant psychological trauma voiced by caregiver's it was obvious that these families are no strangers to trauma and were certainly activated from their child's management of lead poisoning. Psychological support of caregivers is paramount as part of the collaborative therapeutic alliance. Nurses need to focus on supporting caregivers versus the management of the process. Right now the approach is very punitive and negative. The flipping of the approach to a more positive, client centered, us working together approach would be ideal.

Implications for Practice

Nurses work with many individuals and families who are impacted by chronic disease and require ongoing care, treatment, screening and follow-up. Many diseases and illness that require follow-up and case management have high attrition rates and less than ideal outcomes. Lead case management and LFS have an element of coercion or non-negotiables to the process. Many caregivers were surprised when they were informed that they had broken one of these non-negotiables and even potentially risk of being charged with medical neglect. Others knowingly did so but were unprepared for the significance of the potential outcome. Geller and Srikameswaran (2006) discussed the development of mandatory treatment components as 'treatment non-negotiables' in their practice of anorexia nervosa. These practitioners make suggestions on how these non-negotiables should be developed and presented to clients so that therapeutic rapport can be developed and alliances maintained. These non-negotiables are developed using a philosophy that assists in balancing the principles of safety, autonomy, respect

and maintaining a collaborative approach in order to maximize the client responsibility for treatment (Geller and Srikameswaran, 2006). The important issue with coercion or mandatory treatment is the potential that once treatment is completed, the client because they were not engaged, will not be able to maintain without the structure.

Non-negotiables should be thoughtfully established along with sound rationales. These non-negotiables should be transparent, clearly articulated and communicated to the client. Conditions under which these non-negotiables would be implemented should be discussed along with some illustrations. Attention to their delivery, the program, and collaborative process throughout treatment is essential. Clients, who had been involuntarily treated, responded to a survey, and indicated that they understood the need for non-negotiables. Some client did object as they felt they were not treated with respect if a non-negotiable had not been explained and/or was unexpected. Health professionals indicated that non-negotiable were easier to implement when it was clear, understood and had a sound rationale (Geller and Srikameswaran, 2006).

Arbitrary non-negotiables, without rationale or were unclear, resulted in the client perceiving the HP as careless or not thoughtful. The client may have a decrease confidence in the provider and instead of engaging in treatment expended energy on being angry. To improve arbitrary non-negotiables the writers recommend: 1) limited choices in a serious matter with sound rationales for each choice, 2) reflect on whether non-negotiables as necessary or being implemented fairly, 3) be able to explain without uneasiness why it is necessary (Geller and Srikameswaran, 2006).

Non-negotiables without advanced warning, will increase client anxiety and higher anxiety will result in lower readiness for change (Geller, Cockell & Drab, 2001). Surprises also do not allow the client to change their behavior to avoid a non-negotiable and not having

structure and understanding expectations makes clients feel unsafe. The writer recommends: 1) inform the client of non-negotiables as early as possible, 2) ask clients to discuss their feelings about non-negotiables, and 3) provide reminders if it appears a non-negotiable is likely (Geller and Srikameswaran, 2006).

Inconsistent non-negotiables result when they are not enforced or differ based on HP. When this occurs again it decreases the confidence in the HP and also opens up the potential for the client to test the limits. The writer recommends: 1) non-negotiables should be what the team can adhere to and consistently practice, 2) consider eliminating non-negotiables that cannot be concisely implemented, and 3) all team members must be able and willing to implement (Geller and Srikameswaran, 2006).

Personal responsibility is minimized and results when the HP assumes responsibility for the client's responsibilities. This can result in power struggles and increase client resistance. Clients need to be responsible for their treatment. The writer recommends: 1) non-negotiables only pertain to what is necessary, 2) provide options and choices to non-negotiables, and 3) acknowledge and validate client's experiences (Geller and Srikameswaran, 2006). Non-negotiables should be applied in practice in order to maintain the therapeutic alliance. Non-negotiables should be established based on the client safety, autonomy and HP responsibility for providing a safe environment that is conducive to change (Geller and Srikameswaran, 2006).

At the macro level implications related to practice are: 1) nurses need to develop active engagement and policy that ensures continuity of care and management with children with lead poisoning; and 2) addressing society's responsibility for safe housing versus the placing the onus on disadvantaged families who live in this leaded housing stock. Meso level implications related to provision of resources and support to families to empower them to address this issue. At the

micro level nurses need to focus on supporting caregivers versus the management of the process. The process is too punitive and negative and needs to be client centered and collaborative.

In addition, coalitions that pool resources and expertise that create activism to hold communities accountable to address the lead hazards and protect children is essential. Dealing with the root cause which is the lack of health homes for children to live in versus the treatment of the symptoms of lead poisoning is important. This should be framed as an '*our*' problem versus '*your*' problem. As this is a large multifactorial issue that cannot be addressed at only the meso level.

Implications for Education

Lead case management and LFS are essential activities to improving the health outcome for children with lead poisoning. The caregiver plays a pivotal role in mitigating these risk. During the interviewing, it became obvious that many of the caregivers were struggling with caregiver burden. Caregiver burden is defined as “the degree to which a caregiver’s emotional or physical health, social life or financial status has suffered as a result of caring for their relative” (Zarit et al. 1986, p. 260). The caregiver provides not only physical care but often psychosocial support. Caregiving to children with chronic diseases is an added role to an already busy caregiver role. As families become smaller the burden becomes greater (Ekim & Ocakci, 2016). Nurses who provide case management need more extensive preparation on chronic disease impact on not only on the management needs of the client’s illness but support for the caregiver and family as well. With the increase in care being provided in the community and chronicity nurses need more education on how to support families who are trying care for a member with chronic disease. Nurses need training on the most effective ways to provide caregiver education

and information on the disease processes and their management. The key point is being able to provide this education to disadvantage populations as most of the families impacted by lead poisoning are low –income minority families. Studies have shown that these types of interventions have significantly decreased caregiver and child stress. It also increases compliance with medication and treatment regimes, prevents potential issues, and increase feelings of control (Baldaia, 1996). In public health, nurses may not be providing hands on care to families however from the interviews many caregivers had difficulty with understanding lead poisoning, the treatment regimen, and struggled to access this knowledge.

Nurses need to understand the importance of assessing caregivers for stress and providing stress point interventions. These are interventions that are directed towards the caregiver to reduce concerns and stress. Studies have shown that stress point interventions improve parental coping and family functioning. Nurses also need assessment skills to determine if families are experiencing the symptoms of poor quality of life (Melnyk & Feinstein, 2001).

Nurses need education on how to provide caregivers with problem solving skills training. This has been used with caregivers with children with cancer and has demonstrated to be very effective. Caregivers learn to identify the problem, determine options, chose the best one, act and see if it works. Most importantly in the beginning this is done with the support of the nurse (Melnyk & Feinstein, 2001).

Lastly, nurses are taught how to work with caregivers on educational-behavioral interventions. This supports caregivers so they understand what to expect, what is normal and how to support their child developmentally. It also provides strategies for becoming involved with their child and providing care (Melnyk & Feinstein, 2001).

Implications for Research

Lead case management and LFS are essential for the health outcome of the lead poisoned child. This work has discussed repeatedly the high attrition rate and LFU. There are many barriers and social contexts which impact the caregiver's ability to engage in this process. Many of the caregivers indicated that they would participate in a support group. The findings also indicated that many caregivers required some emotional support for their psychological reactions. Lead hazards are challenging to control and for many parents it has proven to be trial and error process. Having access to other parents with experience provides more knowledge, support, and increases confidence in managing their child's illness.

One area of practice that is making a significant impact on chronic disease management, especially in vulnerable populations is shared medical appointments (SMA). This type of appointment is able to increase the length of appointment times, incorporate other specialties and meet the comprehensive needs of the caregiver and child while improving health outcomes, especially of vulnerable populations. Research would be very beneficial to determine if this would be an effective model for lead poisoned children and their caregivers. The shared medical appointment (SMA) model has been used in the treatment of pediatric asthma. Chronic disease appointments usually last much longer and more costly. SMA is a group medical appointment that incorporates other disciplines and is able to deliver one and one medical appointment as well as providing information on disease management, a supportive group environment with other caregivers. Often other members of the health care team can meet with patients and caregivers as well. For example a behaviorist worked with the group to explain management practices for asthma control and the practices were labeled and codes were applied so that both the children and caregivers could remember and internalize. Each child had a history taken and a physical

examination. The group, as a whole, were encouraged to ask questions and the answers were discussed as a group. A five point Likert scale were used to measure satisfaction. Eighteen child-parent dyads rated high levels of satisfaction in all areas. Another questionnaire asked the participants to rate a previous one and one appointment to the SMA and the respondents rated the SMA appointment higher (Wall-Haas, Kulbok & Kirchgessner, 2012)

Evaluation of Quality

Criteria for evaluation and rigor.

The findings were verified through dwelling with the data, comparing the data after each new interview and theoretical sampling to ensure variation. In GT trustworthiness is established through consideration of credibility, transferability, external validity, dependability, conformability of the theory (Artinian, 2009).

Credibility was achieved by using constant comparative analysis which develops an elementary theory that can be generalized to caregivers who are experiencing the process of LFS. This work is transferable and applicable to other caregivers who are also concerned with LFS. At this time LFS is an ongoing issue throughout the US and the globe (Artinian, 2009). During the development of concepts each were validated by participants during the interview by repeatedly asking if they agreed with the researcher's interpretations. External validity indicates the theory fits both the situation in which it was developed and other new situations (Artinian, 2009). It is unknown at this point if this theory fits other LFS programs. All categories and properties were constantly being checked against new data or any changing conditions. Confirmability occurs when the conceptualization of the theory can stand on its own and any new data will extend or modify the theory (Artinian, 2009). At this time it is unknown if the theory will fit lead case management practice. Lastly, themes and patterns when no longer

unique reflects no new themes or patterns would indicate data saturation. A letter was sent out to all participants to provide a member check on the findings. Only one participant was agreeable to participate and validated many of the themes. Lastly the findings of this study are substantiated by matching theories and concepts found in the empirical literature (Giske & Artesian, 2009).

Limitations/Assumptions

The findings of this study are limited by their generalizability to other regions and/or populations outside the Northern Kentucky. The other potential limitation is that many participants offered to interview at the same time thus limiting the researcher's ability to review an interview before carrying out another one. The fact that participants appeared so eager to interview when contacted indicated to this researcher that there was a very important need and potential findings to be discovered. The reinforcing of a policy of medical neglect at the State level during the project timeline may also may change the generalizability to other regions. Another potential limitation is that the findings may not reflect the group of caregivers who are lost to follow-up.

Conclusions

The findings from this study aid in developing a framework for nursing interventions to address barriers to caregivers remaining in case manage and LFS treatment. As chronicity increases as will caregiver burden. It is essential that nursing practice and evolve to provide interventions to identify caregivers who require more support and leverage the necessary resources so they remain in care. This is especially important in illness where mandatory treatment is required.

Table 1 *Guidelines for Blood Lead Level (BLL) Follow-up*

BLL	Screening
5-14 µg/dL	<ul style="list-style-type: none"> • Repeat blood lead level in 12 weeks of the initial, if BLL is still in this range repeat every 12 weeks until blood lead level is < 5 µg/dL. • Establish a tracking system that assures retesting. • Establish Case management.
15–29.9µg/dL	<ul style="list-style-type: none"> • Submit confirmation (see assessment criteria) specimen within one week • Repeat blood lead levels at 1–2 month intervals until: <ul style="list-style-type: none"> -Blood lead level is less than 5µg/dL for 6 months -or as s ordered by the physician • Establish a tracking system that assures retesting and case management • For medical case closure see case closure section • Environmental: Lead hazards have been addressed
30-44.9µg/dL A VENOUS specimen is needed to confirm a diagnosis of lead poisoning at this level.	<ul style="list-style-type: none"> • Same as above
45–69.9 µg/dL A VENOUS specimen is needed to confirm a diagnosis of lead poisoning at this level.	<ul style="list-style-type: none"> • Submit venous confirmation specimen within 48 hours • During and post chelation therapy, retest monthly until: • Blood lead level is less than 5µg/dL for 6 months (capillary specimens are acceptable) • or as ordered by the physician • Establish a tracking system that assures retesting and case management • For medical case closure see case closure section • Environmental: Lead hazards have been addressed
70µg/dL and above A VENOUS specimen is needed to confirm a diagnosis of lead poisoning at this level.	<ul style="list-style-type: none"> • Submit venous specimen within 24 hours • During and post chelation therapy, retest monthly until: • Blood lead level is less than 5µg/dL for 6 months (capillary specimens are acceptable) • or as ordered by the physician • Establish a tracking system that assures retesting and case management • For medical case closure see case closure section • Environmental: Lead hazards have been addressed

(Kentucky Cabinet for Health and Family Services [KYCHFS], 2012, p 5-7).

Table 2

Health Care Costs (2006 USD)^a

Blood Lead Level (µg/dL)	Cost of recommended Medical Action(\$)	Lower bound of affected children(no.)	Upper bound of affected children (no.) ^b	Lower bound Cost (\$)	Upper bound cost (\$)
10-15	74	24,554	120,656	1,816,996	8,928,552
15-20	74	8,185	40,220	605,690	2,976,305
20-45	1,207	6,347	31,189	7,660,829	37,664,611
45-70	1,335	376	1,848	501,960	2,466,585
>70	3,444	64	314	220,416	1,083,104
All levels		39,526	194,227	10,805,891	53,099,158

^A Kemper et al. (1998) provided estimates for the costs of recommended action (inflated to 2006 USD). ^b The upper bound values are calculated assuming that CDC state-level surveillance confirmed cases represent 20.35% of estimates >10 µg/dL derived from NHANES (2003-2006): 39,536 confirmed cases to 194,227 cases as estimated from NHANES (2003-2006).

Table 3 Lead and IQ

BLL (µg/dL)	Lower bound of affected children(no.)	Upper bound of affected children (no.)	Average BLL per group (µg/dL) ^b	Average IQ point loss per µg/dL ^c	Lower bound IQ Loss	Upper bound IQ
2-10	5,632,147	7,400,920	3.13	0.513	9,043,482	11,883,583
10-20	32,739	160,876 ^d	~15	0.19	199,053	978,129
≥20	6,678	32,815 ^d	~20	0.11	46,946	230,690
Totals					9,289,482	13,092,402

^A Data for children with BLLs > 10 µg/dL are estimated from CDC NHANES 2003-2006. Data for children >10 µg/dL are from state-level surveillance and assumes uniform distribution of cases within each BLL group. Lower and Upper bound for 2 –to 10-10 µg/dL group represents 95% CIs for NHANES estimate. ^B Average BLL calculated for 10-20 µg/dL taken as midpoint, and average BLL for > 20 µg/dL group uses the most conservative lower bound (the floor) for the mean. ^C Data from Lanphear et al. (2005) assume uniform decreases within BLL groups. ^d Values calculated assuming that CDC confirmed cases represent 20.35% of all cases, given that CDC confirmed cases represent 20.35% of NHANES estimates for those >10 µg/dL.

Table 4 Lead and Crime

Crime	All crimes per 100,000 residents (no.) ^a	Lead-linked crimes per 100,000 residents (no.) ^b	Total lead linked crimes (no.)	Direct costs per crime (\$) ^c	Total direct costs (\$) ^c
Burglaries	1335.7	38.7	116,541	4,010	467,329,410
Robberies	213.7	0.83	2,499	22,871	57,154,379
Aggravated Assault	352.9	17.9	53,904	20,363	1,097,628,286
Rape	37.6	1.39	4,186	28,415	118,945,567
Murder	8.3	0.238	717	31,110	22,305,512
Totals			177,847		1,763,363,153

^a Calculated using crime incidence data from the Federal bureau of Investigation (2006). ^b Data from Nevin (2006). ^c Data from the Bureau of Justice Statistics (2004); inflated to 2006USD.

Table 5 total costs and benefits of lead control

	Conservative estimates	Optimistic estimate
Total benefit from lead reduction	\$ 192.38	\$270.45
Total cost of lead control	\$11.02	\$1.22
Total net benefit	\$181.37	\$269.23
Cost-benefit	1-17	1-221

All costs and benefits are in billions of 1996 dollars.

Table 6

Table 5. Targeted Screening Rates among Kentucky Children < 72 Months of Age, 2010

Targeted Status	Number of Children Screened	Targeted Screening Rate (%)	Number of EBLI Children					
			10-14 µg/dL	15-19 µg/dL	20-24 µg/dL	25-44 µg/dL	45-69 µg/dL	>=70 µg/dL
Targeted	6837	9.90%	87	32	12	36	16	2
Non-Targeted	20305	7.50%	102	34	10	15	0	0

Data Source: KY CLPPP Surveillance System

Table 7

Household Income Northern Kentucky HOME Consortium				
	1990	2000	2007	2012
Total Households	31,972	32,273	31,534	31,273
Household Income				
\$0-\$9,999	25.1%	14.8%	13.2%	12.4%
\$10,000-\$14,999	11.1%	8.4%	6.2%	5.4%
\$15,000-\$19,999	10.7%	8.2%	6.7%	6.3%
\$20,000-\$24,999	9.8%	7.9%	7.0%	6.6%
\$25,000-\$29,999	8.8%	8.4%	6.8%	5.0%
\$30,000-\$34,999	8.3%	7.1%	6.7%	6.0%
\$35,000-\$39,999	6.8%	6.7%	5.6%	6.2%
\$40,000-\$49,999	8.8%	10.7%	10.5%	9.9%
\$50,000-\$59,999	4.8%	8.2%	9.2%	8.3%
\$60,000-\$74,999	3.5%	8.3%	9.5%	10.9%
\$100,000-\$124,999	0.3%	2.2%	4.4%	5.6%
\$125,000-\$149,999	0.3%	0.9%	1.8%	3.3%
\$150,000+	0.2%	1.5%	2.8%	3.7%
Average Household Income	\$25,683	\$40,377	\$43,623	\$47,075
Median Household Income	\$21,357	\$31,577	\$38,060	\$42,114
Per Capita Income	\$10,069	\$16,682	\$18,519	\$20,032

(Northern Kentucky Home Consortium, 2008).

Table 8
Household Details
Northern Kentucky HOME Consortium 2000

Population & Household Overview		
Population	78,117	
Household Population	76,496	
Family Population	79.1%	60,485
Non-family population	21.8%	16,691
Households	32,273	
Family Households	58.7%	18,957
Non-Family Households	41.3%	16,691
Households by Presence of Children		
Total Households with children	10,976	
Family Households with children	10,819	
Married Couples	54.2%	5,953
Male Household -No spouse	8.9%	972
Female Household -No spouse	35.5%	3,895
Non-family Household With children	156	
Male Household -No Spouse	1.1%	125
Female Household -No Spouse	0.3%	32
Total Households Without children	21,298	
Family Households without children	8,139	
Married Couple	27.7%	5,907
Male Household -No Spouse	3.1%	660
Female Household -No Spouse	7.4%	1,573
Non-Family Households without Children	13,159	
Male Household -No Spouse	30%	6,392
Female Household -No Spouse	31.8%	6,768

(Northern Kentucky Home Consortium, 2008).

Table 9 Rater 1 and 2 Crosstab of Ratings

Rater 1 and 2 Crosstab of Ratings					
			Rater 2		Total
			Important	Not Important	
Rater 1 (C1)	Important	Count	611	332	943
		% within Rater 1	64.8%	35.2%	100.0%
		% within Rater 2	85.0%	18.7%	37.8%
		% of Total	*24.5%	13.3%	37.8%
	Not Important	Count	108	1444	1552
		% within Rater 1	7.0%	93.0%	100.0%
		% within Rater 2	15.0%	81.3%	62.2%
		% of Total	4.3%	*57.9%	62.2%
Total		Count	719	1776	2495
		% within Rater 1	28.8%	71.2%	100.0%
		% within Rater 2	100.0%	100.0%	100.0%
		% of Total	28.8%	71.2%	100.0%

* the diagonal values are where the raters agree

Table 10

Symmetric Measures					
		Value	Asymp. Std. Error ^a	Approx. T ^b	Approx. Sig.
Measure of Agreement	Kappa	.607	.017	30.927	.000
N of Valid Cases		2495			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Table 11 Theoretical Concepts

Concepts	Dimensions	Properties
Core-Concept <i>Tells you if what you are doing is working</i>	Psychological Reactions Caregiver Coping Meeting Expectations	Caregiver responses to their child's diagnosis of an elevated blood lead level LFS information
Psychological Reactions	Discovery Psychological Involvement with the child Long term fear and anxiety, guilt and stigma	Fear, worry, "freaked out", sadness, depression, tiredness, guilt, shame, powerlessness, anger, embarrassment, loss of role stature.
Parental Coping	Doing Vigilance Knowledge Relationships, Supports and Barriers	Caregiver carrying out the necessary activities to lower ELL with the assimilation of knowledge from HCP and support. This also means watching for lead hazards in the home as well as the child displaying symptoms of ELL.
Meeting Expectations	Caregiver role and social expectations	Role, responsibility, spiritual obligation.

	Healthcare and system expectations	Perceptions of the role of health care and the system in supporting in lowering ELL. Unequal standards and expectations for the system versus caregivers.
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Figure 1

Map 2.

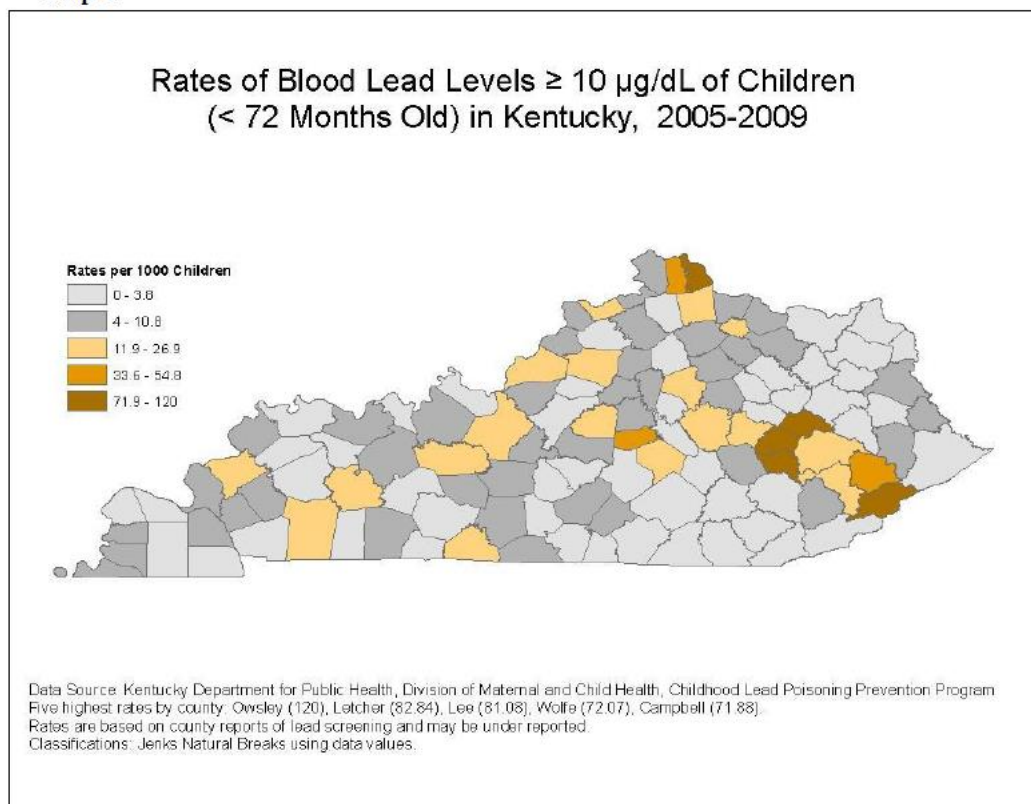
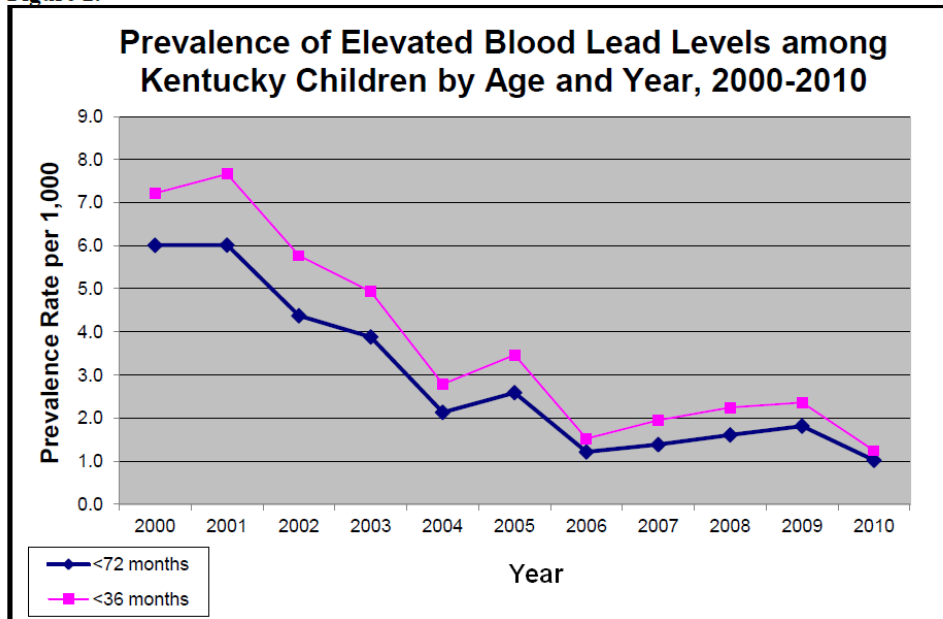


Figure 2

Figure 2.



Data Source: KY CLPPP Surveillance System; Kentucky State Data Center, 2000-2009 Population Estimates; and US Census Bureau, American Fact Finder, 2010 Population Data.

Figure 3

Map 2.

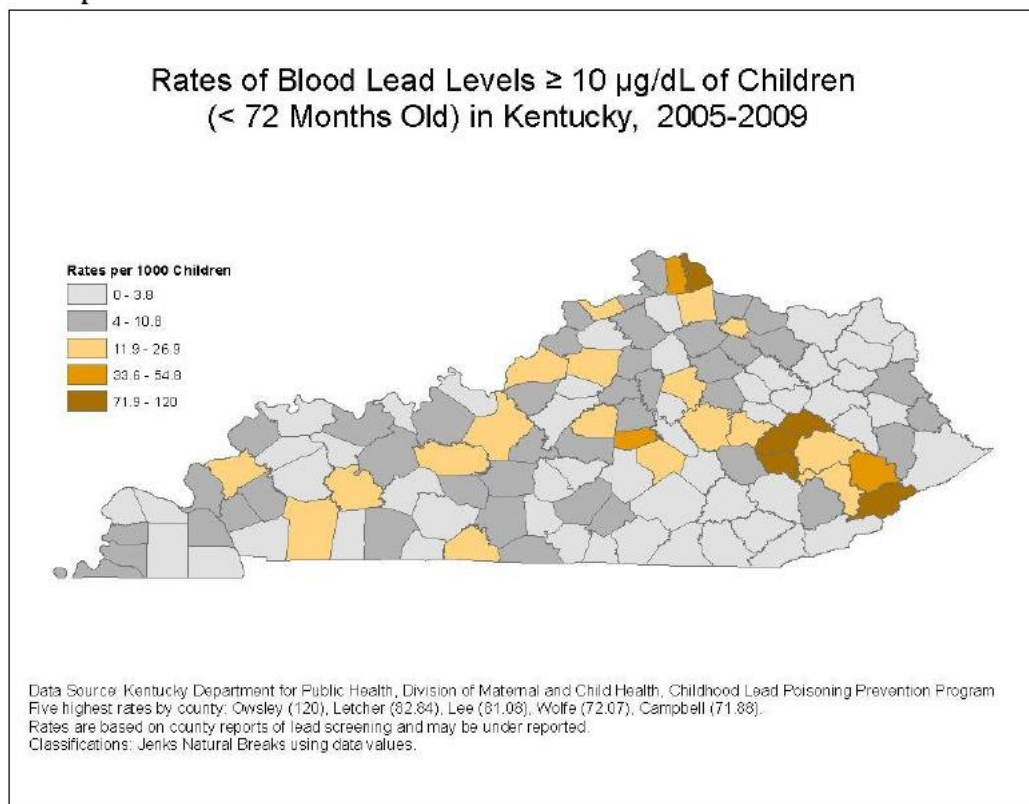
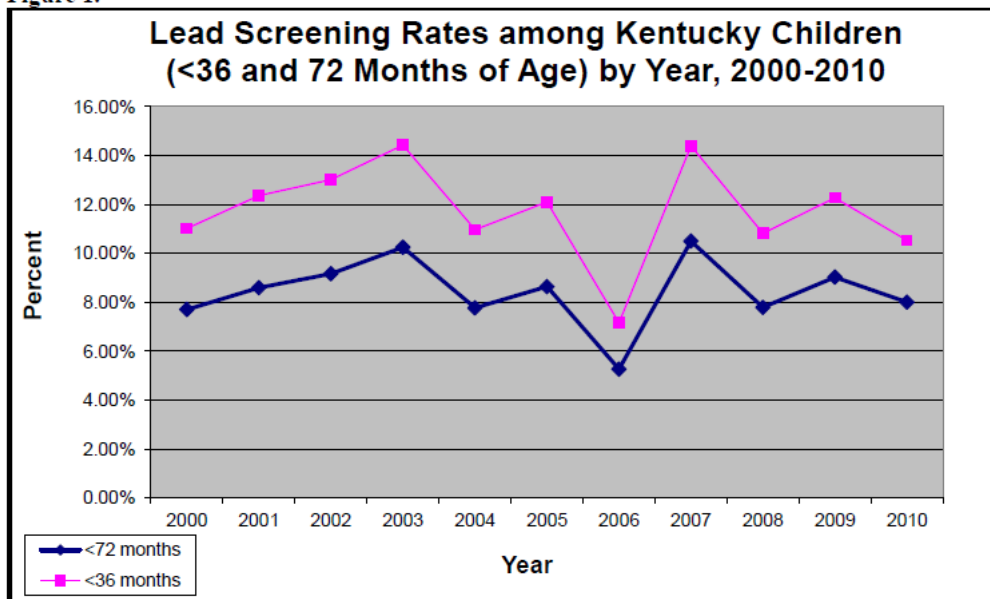


Figure 4

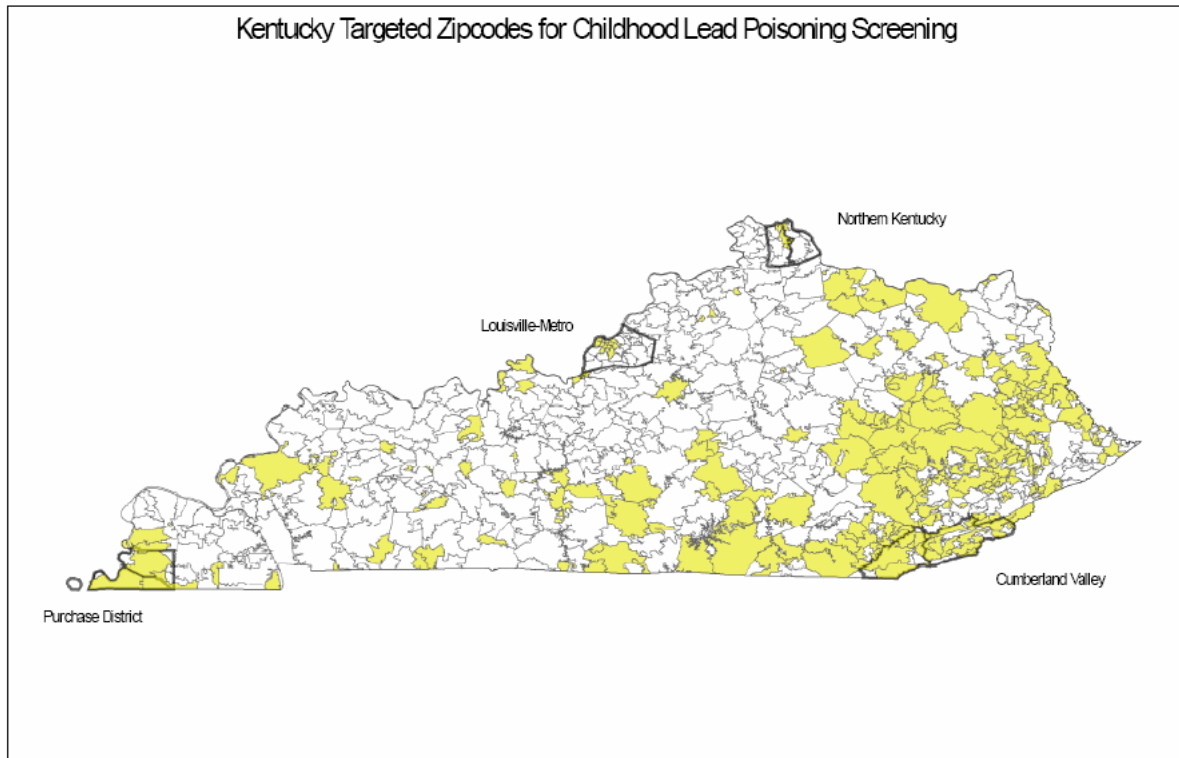
Figure 1.



Data Source: KY CLPPP Surveillance System; Kentucky State Data Center, 2000-2009 Population Estimates; and US Census Bureau, American Fact Finder, 2010 Population Data.

Figure 5

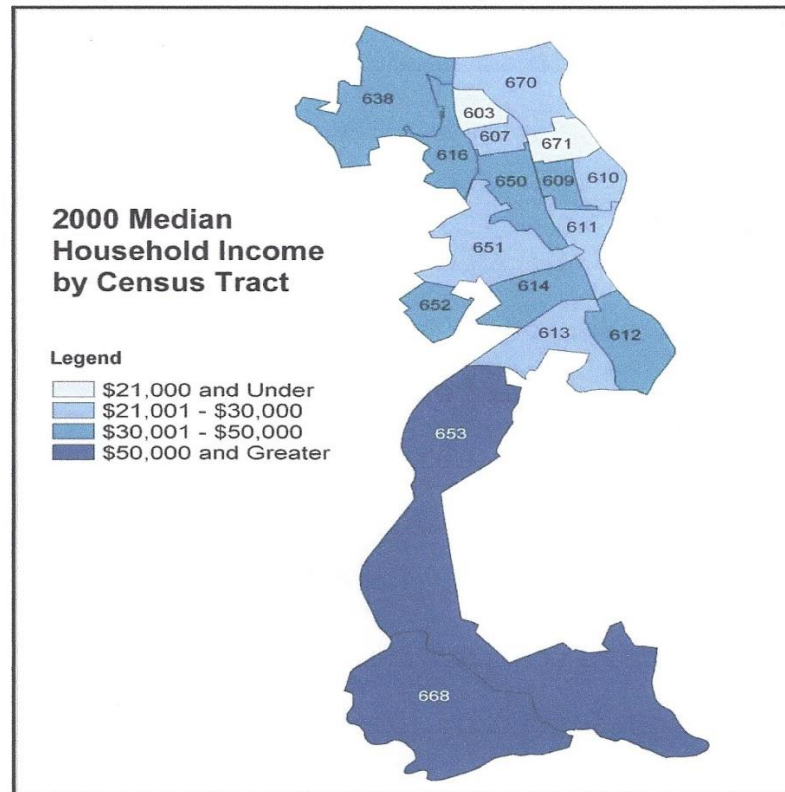
Map 3.



Data Source: KY CLPPP Surveillance System and 2000 US Census Bureau Population and Housing Data

Figure 6

Covington, Kentucky



In 2000 15.5 percent of families in Covington lived in poverty. The percentage jumps to 30.3 percent when households with related children under 5 years of age are considered. When families with female-headed household, no husband present and children under age 5 years are considered, the percentage living in poverty increases to 59.5 percent.

Figure 7

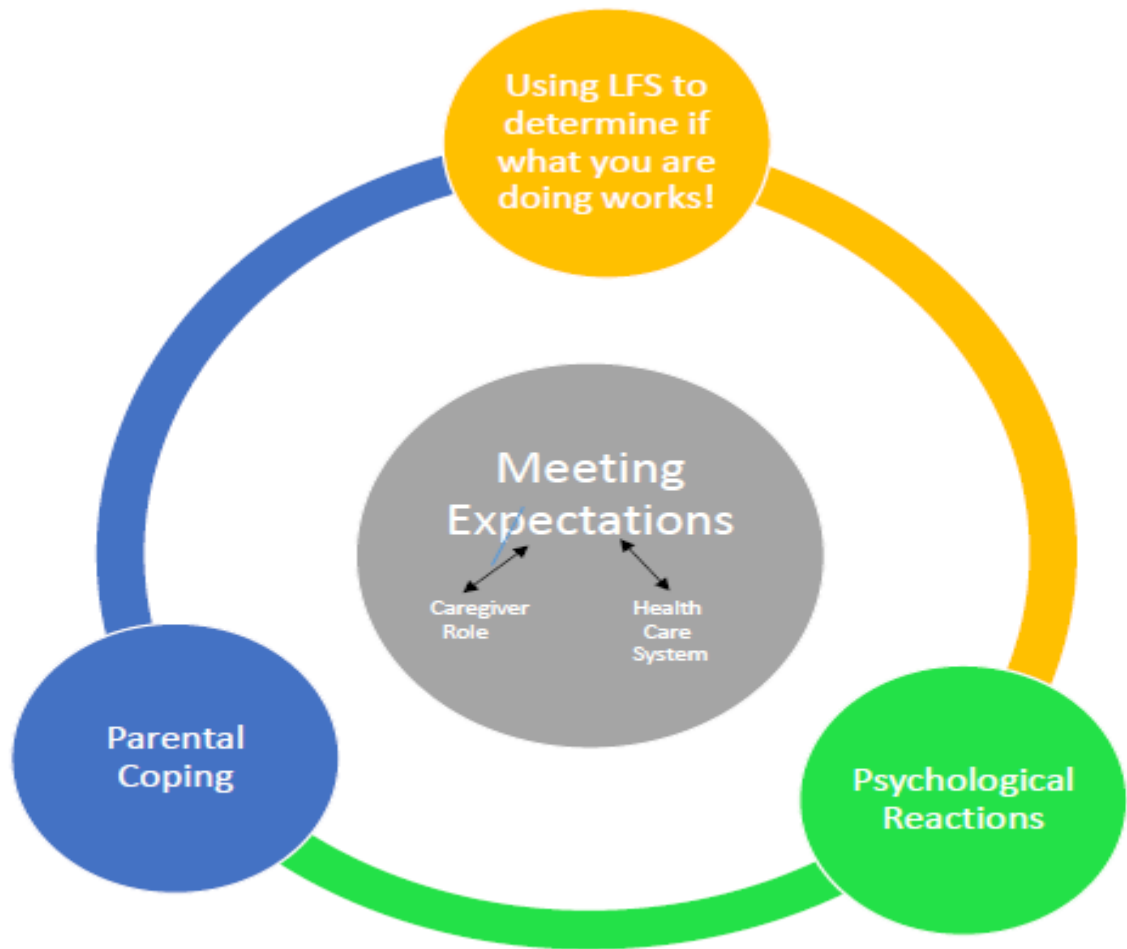
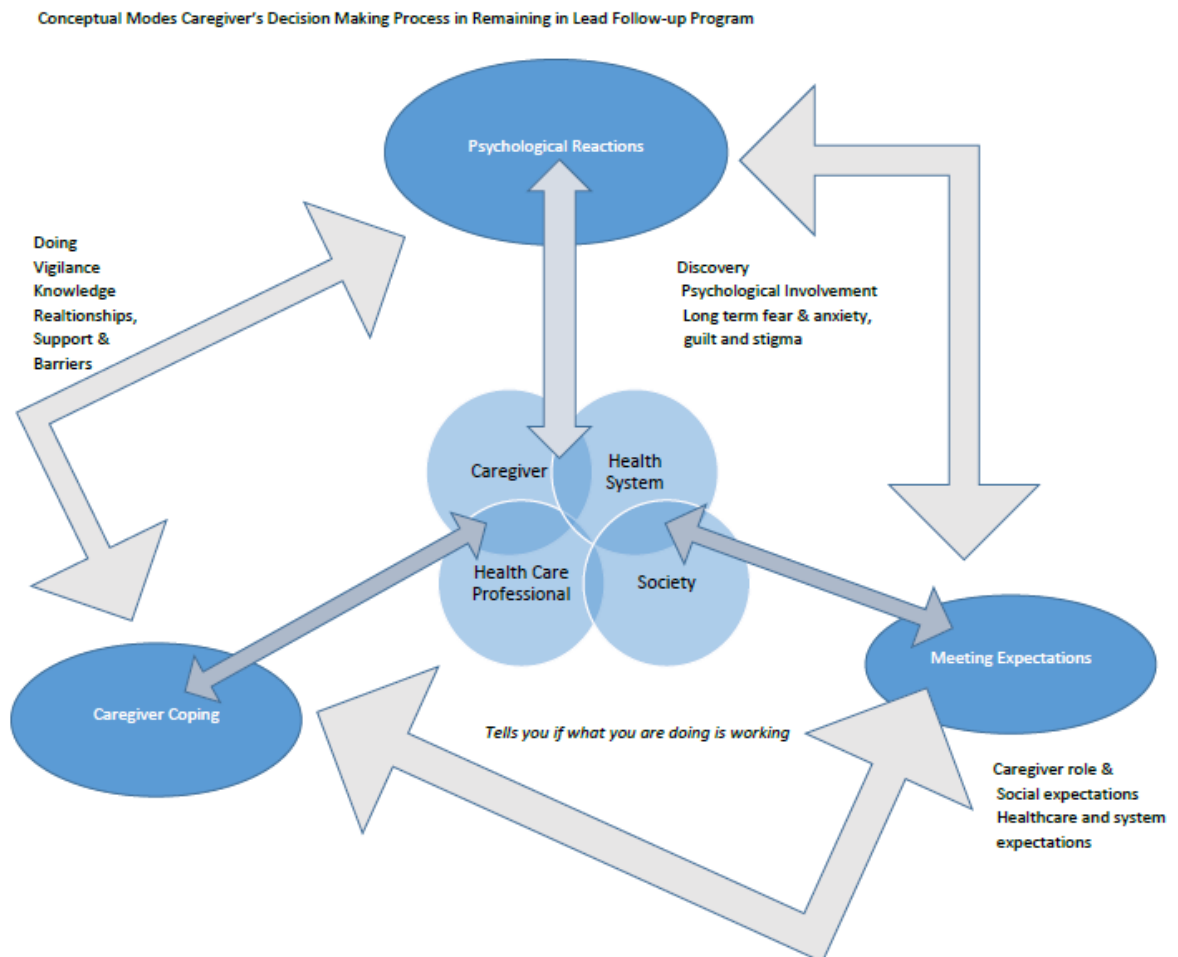


Figure 8



Appendix A

Background of the Methodology

Caregivers who are caring for their lead poisoned child/children and are participating in LFS programs are well situated and specific to the phenomenon of the process of deciding whether to remain engaged in this program. Grounded theory methodology allows for the voices of caregivers to be heard and can offer better understanding of what and how ‘meanings’ are constructed and how caregivers manage these many situations and problems, as well as, the health of their child. Grounded theory is a qualitative research design that is a good fit when the inquirer wishes to generate a framework or theory that explains human behavior in context (Glaser & Strauss, 1967; Glaser, 1978). “Thus, human behavior that is related to health issues, developmental transitions, and situational challenges is well suited to grounded theory research in nursing” (Munhall, 2007, p. 244).

Symbolic Interactionism

Grounded theory is rooted in symbolic interactionism (SI) and reflects a pragmatist philosophical tradition, “a theoretical perspective that assumes society, reality, and self are constructed through interaction and thus rely on language and communication” (Charmaz, 2006, p. 7). The assumption of interaction is dynamic and interpretive and results in how individuals create, enact and change meanings and actions (Charmaz, 2006). Symbolic interactionism rests on three premises; 1) human beings act towards things based on the meaning that the object holds, 2) meanings of things are a result of social interactions with fellow humans, 3) these meanings are managed and modified through an interpretive process that each individual experiences (Blumer, 1969). The methodological presentation of symbolic interactionism maintains that; “social action must be studied in terms of how it is formed; its formation is a

very different matter from the antecedent conditions that are taken as the “causes” of the social action and is not covered by any specification of such cases” (Blumer, 1969, p. 57).

Interactionist theory is a dialectical circle; the individual is the author of his/her social world but is also a product of society. “Self is an expression of the entire situation (interactional field) in which the individual is acting, while the situation is the reflection of the totality of selves engaged in an interactional encounter” (Shalin, 1986, p. 17). Individuals do the choosing and identify with the ‘self’ that is called for in that situation. Exposure to different fields may result in an individual changing their actions and to choose alternative ‘selves’. The actions of the individual in response to the interactional field are non-random, with an underlying pattern that can be predictable and expressed in probabilistic terms (Shalin, 1986).

For example, in the beginning ‘lead dust’ to caregivers may hold little significance other than a signal it was time to dust their home. To a real estate agent, it is an item for disclosure and possible risk to selling a home. To health care providers ‘lead dust’ is a preventable environmental disease that can significantly impact on a child’s health. For a caregiver, once their children become lead poisoned and the source of lead is described to them ‘home dust’ takes on a whole new meaning. This meaning is not developed in isolation but with interactions with others such as health care providers, case managers, environmentalist, lead nurses, fellow neighbors, friends and family. Overtime, depending on the outcome of their child’s health and how successful they are at being able to modify the living environment, the caregiver’s meaning for ‘lead dust’ may change significantly.

Snow (2003) believed that individual’s actions were not based only on the meaning given to an object but rather was concerned with 1) how meanings became routine or taken for granted, 2) what contexts, relationships, or structures support acceptance of these meanings, and 3) do the

meanings serve as the basis for action, or the solving of a problem. Snow's premises lead to the principle of emergence which sees the social contexts and SI playing a role in the emergence of social, emotional and cognitive changes in individuals. Snow contends that often these changes are invisible and not noticed by others until they cause disruption in that individual.

For example, many communities have become so accustomed to having lead in the housing stock that they do not see it as a unique issue or give it the recognition it deserves from a health perspective. Landlords may say to caregivers "there is lead everywhere" when addressing lead hazard concerns in the living environment. Lead case managers indicate that the average BLL for some communities is "just higher". Thus, many times there is little support to change the housing stock as it is seen as a fruitless effort as the community itself is 'leaded' and the social structure allows for these lead hazards to remain both inside homes and out.

Blumer (1969) contends that to understand the world the researcher must analyze the participants' actions and interactions. He/she must be able to interact with participants and see things from their perspective and their natural context. Thus, to understand the caregivers participating in LFS from a SI perspective the researcher using GT must be able to consider the world through the participant's eyes without making assumptions. The establishment of rapport, and respect by the researcher assists in understanding how meanings were formed, what they are and how they drive the actions of individuals (Charmaz, 2006).

Grounded Theory in Healthcare and Nursing Research

The power of research has a great influence in the development of a body of knowledge and can be restrictive or liberating depending on the methodology and supporting ontology (Munhall, 2007). The use of "qualitative research method seeks to be of the liberating, illuminating, and emancipatory kind" (Munhall, 2007, p. 78). Grounded theory is currently used

by many health care researchers and is recognized not only for its emphasis on theory development but the interpretation by the researcher of the participant's viewpoint, in what is heard, observed or read. Grounded theory is the study of qualitative data which assists the researcher to verify not only the findings but also generate an explanation for these findings (Glaser & Strauss, 1967) and has become a commonly used methodology in qualitative research in nursing, education and many other disciplines (Miller & Fredericks, 1999).

Historical Background of Grounded Theory

To truly understand GT, it is essential to have the knowledge of its historical beginnings, as well as, the players in the development of the theory and its evolution. Grounded theory was discovered by Glaser and Strauss when they were analyzing their own research decisions. Strauss had a sociology degree from the University of Virginia and Master and Doctoral degrees in sociology from the University of Chicago. His advisor Herbert Blumer had urged him to take a class in symbolic interactionism which had previously been developed by George Mead. He was recruited by University of California San Francisco (UCSF)'s dean of the school of nursing to support the scientific foundation of nursing program and develop a Doctor of Nursing program (Stern, 2009).

Glaser earned an undergraduate degree at Stanford in 1952 and spent a year traveling in Europe and then enrolled in the University of Paris and studied literature. The US was drafting men into the military and Glaser spent two years serving in Freiberg, Germany and studying literature at the University of Freiberg. Afterwards Glaser returned to the US and commenced studies in descriptive statistics at the University of Columbia with Lazarsfeld and Merton. He returned to California, met Strauss and joined UCSF as a research assistant (Stern, 2009).

Glaser assisted Strauss with his work on *Awareness of Dying* and it was during this work that both men realized they had both used different methods than had been applied to the data before (Stern, 2009). Strauss felt that his experience in theory development and symbolic interactionism was influencing this approach whereas Glaser felt his constant comparison of the data came from his descriptive statistics experience. Together they published the book *The Discovery of Grounded Theory*. They continued their work together and published three more books. *Awareness* (Glaser & Strauss, 1965) and *Discovery* (Glaser & Strauss, 1967) were the most popular (Stern, 2009).

In 1978 Glaser published *Theoretical Sensitivity* holding onto the classical method that had previously been developed. Strauss worked with another colleague to publish *Grounded Theory*. Glaser took offence to this publication indicating he felt that it undermined his intellectual property and published a scathing retort to this publication indicating that the process outlined in this text did not allow for the emerging of the theory but forced the data into categories. Although Glaser and Strauss were not able to resolve their differences before Strauss passed away in 1996, Glaser continues to publish and dedicate all his books to his mentor Strauss. Both men have been recognized for their huge impact in this research field (Stern, 2009).

As a result, in the split in the original authors on grounded theory, publication of other texts resulted in the creation of divergent GT methodologies. Today the term GT has become an umbrella term with a range of many practices (Hesse-Biber, 2010). Schatzman joined the group at UCSF and in 1973 published a text *Field Research: Strategies for a Natural Sociology* that was co-authored with Strauss who felt it was not GT but dimensional analysis (Morse, 2009). Other students who worked with both Glaser and Strauss developed work that reflected the

influences of both teachers. Charmaz in 2006 developed constructivist grounded theory and in 2005 Clarke developed situational analysis which incorporates diverse data sources and includes postmodernism (Morse, 2009).

Methods

The Process of Grounded Theory

Grounded theory is a process that allows researcher to determine the main concern of a group and learn what behaviors are used by the group to resolve this concern (Glaser & Strauss, 1967). Glaser and Strauss state that a theory must;

Provide clear enough categories and hypothesis so that crucial ones can be verified in present and future research; they must be clear enough to be readily operationalized in quantitative studies when these are appropriate. The theory must also be readily understandable to sociologist of any view point, students and to significant laymen.

Theory that can meet these requirements must fit the situation being research, and work when put into use. By “fit” we mean that the categories must be readily (not forcibly) applicable to and indicated by the data under study; by “work” we mean that they must be meaningfully relevant to and be able to explain the behavior under study (p. 3).

This approach allows for theory to be explained in context and is useful when little is known about the phenomenon (Wuest, 2007). In turn the researcher articulates this understanding with words or phrases that reflect the participants experience thus developing a theory (Glaser & Strauss, 1967). The process is inductive and requires that the researcher use constant comparative analysis, developing a hypothesis and collects more data while re-checking data already collected for any new concepts against the new data (Glaser & Strauss, 1967). In

comparative analysis the “facts are replicated with comparative evidence, either internally (within the study), externally (outside a study), or both” (Glaser & Strauss, 1967, p. 23).

The emerging theory is developed through theoretical sampling and the data collection is guided by this process and is described as pointing “to the next steps-the sociologist does not know them until he is guided by emerging gaps in his theory and by research questions suggested by previous answers” (Glaser & Strauss, 1967, p. 47). In theoretical sampling the participants are selected based on the descriptive needs of the emerging concepts and theory which should dictate the strategies of sampling (Morse, 2007). Theory is then developed around one concept at a time even though the data may have identified multiple concepts for exploration. The other assumptions include; 1) the main concern and core category will emerge with consistent use of the methodology, 2) social organization of a group that exists will be discovered, 3) the participant’s concerns not that of the researcher are the focus of the research. Glaser has continued to develop the process of GT which is referred to as Glaserian grounded theory. Glaser indicates that the researcher must remain long enough in the setting to fully understand and allow the participant’s concerns to emerge (as cited in Artinian, 2009).

Wuest (2000) indicated that GT can be applied using different approaches. These approaches are acceptable if the chosen approach builds on the use of the constant comparative method to identify the main concerns of the subjects and how the subject’s concerns are resolved. In grounded theory discovery or emergent fit mode can both be used.

Social Constructivism

Charmaz (2006) after studying both Strauss and Glaser adopted the SI underpinnings and class GT with a constructivist reality focus. Social constructivist (SC) GT is a part of the interpretive tradition and shares the same orientation of trying to understand the world view

(Charmaz 2006). “Interpretive theory calls for the imaginative understanding of the studied phenomenon. This type of theory assumes emergent, multiple realities; indeterminacy; facts and values as linked; truth as provisional; and social\life as processual” (Charmaz, 2006, p. 127). Interpretive theory fits in with Mead and Blumer’s SI and the researcher interprets the participant’s meaning and actions and participants in turn interpret the researchers’. Interpretive theory not only looks at the overt process but also delves into the implicit meanings and processes (Charmaz, 2006). Schwandt (2000) likens this to a psychological reenactment such as understanding why an actor does what he/she does in terms of motives and the viewer’s historical knowledge. Interpretivism recognizes that one can break out of one’s usual circumstances to reproduce meanings or intentions of another.

“A constructivist view means more than looking at how individuals view their situations. It not only theorizes the interpretive work that research participants do but also acknowledges that the resulting theory is an interpretation” (Charmaz, 2006, p. 130). The theory does depend on the researcher’s view and with this approach the researcher learns how, when and to what extent the concept under study is embedded and hidden in larger positions, networks, situations, and or relationships in the world. As a result, differences and distinctions between individuals become more visible along with hierarchies of power, communication, and the strategies to maintain and continue with these differences and distinctions. To use this theory the researcher must be aware and alert to these conditions that arise to maintain these differences and distinctions and understand that data and the analyses are of SC (Charmaz, 2006).

The use of constructivist GT requires that the researcher have a “reflexive stance toward the research process and products and consider how their theories evolve.... Analysis is contextually situated in time, place, culture, and situation” (Charmaz, 2006, p. 131). The

researchers try to become aware of their preconceived ideas and how they are impacting on the research and come to the realization that they can import ideas into the work if they remain unaware of these starting assumptions (Charmaz, 2006). Schwandt (2000) also calls these views as ‘meaning realisms’ which are entities that are fixed, can be discovered but can also exist independently of the interpreter.

Reflexivity and Situating Self

As a nurse who is white, Canadian born and middle class, I have always been intrigued by how caregivers make health decisions for their children. The process of making these decisions seems to be very much different than making their own health decisions. Most caregivers appear to want what is best for their children but at the same time must also balance needs in their lives as well. Many of the decisions that caregivers make, especially when it comes to a lead poisoned child, have a lasting impact on their offspring’s health.

During the completion of a master’s thesis I explored the ‘lived experience’ of caring for a lead poisoned child. It was during this work that I was exposed to caregiver’s decisions to become LFU. This decision was not just based on the impact LFS had on the child but the family as well. It was a decision that was also reflected in the lack of support by the system and how frustrating it was to navigate. Caregiver appeared to weigh the pros and cons to remaining engaged in LFS and it was a decision not made lightly. When the caregiver did opt out of LFS the decision not only impacted on their child’s health but put the family unit at risk for losing custody of their child to a charge of medical neglect and losing services such as WIC.

As a nurse who has worked in acute, chronic, community care, as well as, the mental health system I have seen firsthand the barriers to accessing care, support and assistance for underserved and low-income families and caregivers. I have worked as a case manager for

CLPPP and have felt very frustrated and often helpless when working with caregivers and their children especially when I have had to enforce regulations and navigate the barriers to access resources or care for them. These feelings of frustration and my quest for nursing knowledge to improve practice and ultimately the health outcomes for this group has led me to use my expertise and examine the social contexts and processes that impact on the decision-making process caregivers undergo to remain engaged in LFS.

My stance is mostly pragmatic and constructivist in orientation and I believe that individuals are active beings who create their own meanings and develop practical actions to solve their own problems (Charmaz, 2006). To understand caregivers of lead poisoned children one must try to understand how they feel, what they know, and how they cope. It is important to observe, to communicate in a manner of empathy, and respect. Thus, by attempting to better understand caregiver's experiences I can advocate for them and develop knowledge that perhaps can clarify the barriers and facilitators to change practices so that these children will remain in LFS.

Nursing is situated in the positivist tradition with emphasis on evidence-based practice that focuses on randomized clinical trials as being truth and a medical perspective on nursing evidence (Fawcett, Watson, Neuman, Hinton Walker, & Fitzpatrick, 2006). Acknowledging that I have been educated to this orientation and I operate under this truth as a nurse is imperative and not to be ignored. Nursing however is holistic in its practice and is an art form and encompass the five separate senses of nursing art which are the nurse's ability to: 1) grasp meaning in patient encounters, 2) an establish a meaningful connection with the patient, 3) skillfully perform nursing activities, 4) rationally determine an appropriate course of nursing action, and 5) morally conduct his or her nursing practices (Johnson, 2006). All these perspectives will allow me to

consider various questions on practice besides what the best evidence for practice is. For example, what is the current practice, what is working, what is not? Do clients find the present practice acceptable? Is the intervention realistic for this group? Is it cost effective? Is it burdensome? Lastly as a public health nurse social justice is a central value in not just in public health but nursing as well. The main goal of public health nursing is to ensure that the common burdens and benefits are equitably shared throughout society. The basis of social justice is that health care is a right and the goals are health equity and population health (Lynde Hamilton & Chalupka, 2012).

After reading grounded theory I was very concerned with Glaser's stance that the researcher should approach the research without preconceived ideas and as a blank slate (Artinian, 2009). With my strong orientation in public health, nursing and clinical experiences I was very concerned that I would not be able to do this. I was actually very concerned that the subtleties of working with an underserved population would also be lost if I was to approach the research in this manner. I was very happy to find the SC approach to GT. In constructivist GT the researcher takes a reflexive stance towards the research, the process, and the outcomes. Consideration is given to how the theory evolves and should reflect both the researcher and the participant's interpretation of the meanings and the actions. As GT is based on social process, the research is also seen as a social process. Constructivists pay close attention to being aware of their presuppositions and how they will impact on the research (Charmaz, 2006).

Explanation of Grounded Theory as a Process

The components of GT practice are; 1) data collection and analysis occur simultaneously, 2) the construction of analytical codes and categories not from preconceived ideas but the data itself, 3) using a constant comparative method during each stage of analysis, 4) the development of

theory is completed at each step of data collection and analysis, 5) memo-writing is used to expand on categories, narrow their properties, define relationships between categories and identify any gaps, 6) sampling is carried out to develop theory construction not to result in a representative population, 7) literature review is carried out after the development of the theory for an independent analysis, narrow properties development, and assist with the advance of data collection and analysis (Glaser & Strauss, 1967; Glaser, 1978; Strauss, 1987). Grounded theory is systematic, inductive method of inquiry, with the intent of constructing theory. Substantive theory can be defined as an interpretation or explanation in most commonly areas of human concern such as education, formal organizations or family relationships (Bryant & Charmaz, 2007). Thus, GT is a design that generates an explanation versus prediction and can provide a framework for further study as it is generated or grounded in the data which are the views of participants (Creswell, 2007; (Strauss & Corbin, 1998).

Constant Comparative Method

Constant comparative method is a method of analysis that is inductive and compares the data with data, data with category, and category with concepts. Data collection and analysis occur simultaneously and once data is collected it should be coded before moving to the next set of data. Comparisons of earlier and later data interviews and making sequential comparisons assist with the analysis. These analyses are comparing data for similarities and differences and help to define a view of the process, action, or belief held by respondents and allows for more awareness of the beliefs that the researcher may impose upon the data (Charmaz, 2006). Such strategies allow for categories to become dense and help to guide theoretical sampling. Coding assists with the comparison method by allowing the comparisons of initial codes to be organized

and separated, as well as, *in vivo codes* that have key words from participants, and are characteristic of social worlds and organizational settings (Charmaz, 2006).

In GT, coding is a process of defining what the meaning of the data is. The GT researcher develops codes from the data by defining what he/she sees. The codes emerge as the researcher studies them. This is different from quantitative research in that the researcher develops preconceived categories and attempts to fit the data into these categories (Charmaz, 2006). There are two stages to GT coding, the initial phase where each word, line, or segment of data is named and the second a more focused selective process that uses “the most significant or frequent initial codes to sort, synthesize, integrate and organize large amounts of data (Charmaz, 2006, p. 46). Once focused codes are developed the data is once again compared to newly develop focused codes which assist with further refining of the codes (Charmaz, 2006).

Data analysis is completed using constant comparative method and the data is compared both within and between interviews, labeled and given codes (Glaser & Strauss, 1967). Grounded theory coding is the process of defining what the meaning of the data is about. The GT researcher develops codes for the data by defining what he/she sees. Analysis of the data begins with “inductive identification of substantive codes to name what is happening in the data, often with more than one code being assigned to a particular data segment (phrase, sentence, and paragraph)” (Wuest, 2006, p. 252). There are two stages to GT coding, the initial phase where each word, line, or segment of data is named and the second a more focused selective process that uses “the most significant or frequent initial codes to sort, synthesize, integrate and organize large amounts of data (Charmaz, 2006, p. 46). This is different from quantitative research in that the researcher develops preconceived categories and attempts to fit the data into these categories (Charmaz, 2006).

Codes are grouped into categories that are at the descriptive level of the study. The analysis at this point becomes theoretical in nature through coding, diagramming and reduction. This analysis is completed through the theoretical view of the participants with linkages of concepts and the dropping of other variables that are unrelated. More clarification is completed to saturate the concepts and clarify the relationships. Lastly the literature is theoretically sampled to support the emerging theory and serves as a comparison as well (Wuest, 2007).

Theoretical coding moves focused codes to the conceptual level and helps to explain how the substantive codes relate to one another, and specify possible relationships (Charmaz, 2006). Glaser (1978) indicated theoretical coding may include analytical categories such as causes, contexts, contingencies, consequences, covariances, and conditions. For example, a category may explain: “Under what circumstances does this category occur?” or “What was the cause that resulted in this category?” Categories that answer these questions would be linked together and may help the categories to not only be more coherent and comprehensible but to clarify specific conditions. It might also outline the temporal and structural order, conditions under phenomenon changes, outlines the consequences and what the participants strategies are for dealing with these (Charmaz, 2006).

Memos capture the researcher’s thoughts, as well as, the comparisons and connections that are made and assist with future questions and directions that need to be pursued (Charmaz, 2006). “Memo writing is the pivotal intermediate step between data collection and writing drafts of papers...Memo writing constitutes a crucial method in grounded theory because it prompts you to analyze your data and codes early in the research process” (Charmaz, 2006, p. 73).

Theoretical Sampling. In GT excellent data is collected when there has been careful sampling (Morse, 2007). Theoretical sampling is based on the researcher’s decisions about how

to collect the data based on the expertise of the researcher through interviews, observations, and /or documents and data. In the beginning the sampling will be a convenience sample based on accessibility. This type of sampling is used to provide an overview of the scope of the phenomenon, to establish dimensions and boundaries, and the trajectory of the project (Richards & Morse, 2007). This process still requires that persons must be experts and experiences the phenomenon under consideration. Next sampling will be purposeful based on the initial analysis of the interviews. Participants are chosen who are going through a specific stage. Sampling in this manner allows for the confirmation of the trajectory and a full description of that stage (Morse, 2007). Next the participants are selected based on the descriptive needs of the concepts and theory and these descriptions outline the sampling strategies and goals (Charmaz, 2006; Glaser, 1978). The researcher seeks out participants who have had responses or who have had significant experience with the concept under consideration. Participant's stories may be used to verify the theory or to provide supplemental information about relationships between categories (Morse, 2007). Lastly theoretical group interviews can be used to expand or verify the emerging theory. Theoretical groups are convened in small number of participants to provide missing information, refine data collection, complete the saturation process or anything else that researcher requires. It should be noted that the participants are not being asked to confirm the analysis but are still in the data collection mode (Morse, 2007).

Theoretical Sensitivity

Theoretical sensitivity is the ability of the researcher to conceptualize and develop a theory by constant comparison of the data. It is taking what the researcher 'knows' and developing it in theoretical terms (Glaser & Strauss, 1967). "The researcher does not go blank or give up his knowledge. He goes sensitive with his learning which makes him alert to [the]

possibility of emergence and how to formulate it conceptually” (Glaser, 1998, p. 123).

Researchers bring different theoretical sensitivities to the study. Some of these sensitivities may be stimulated by review of literature on the characteristics of the concern, historical review to the phenomenon, or spending time in the community or location of the participant (Glaser, 1978; O’Neil Green, Creswell, Shope, & Plano Clark, 2007). Another important consideration is determining how the discipline of nursing, the researcher’s work clinically with caregivers of lead poisoned children, and personal experiences impact on ‘the meaning’ of the data and what the relevant meaning is to the participant (Giske & Artinian, 2009).

Memo Writing

Memo writing is an intermediate step between data collection and drafts of the research findings. Memos assist with the analysis and ideas about the codes (Glaser, 1998). Memos are written successively and assist to keep the researcher involved in the analysis at every step and increase the level of abstraction of ideas. Memos also help to capture and track the researcher’s thoughts and the connections that are made. It also assists with tracking of data that is not used and helps to illuminate how the selection of data is made. Memos can also serve as an audit trail of researcher’s thoughts (Charmaz, 2006).

Core Category

The primary theme of the research which “consists of all the products of the analysis condensed into a few words that seem to explain what this research is all about” (Strauss & Corbin, 1998, p. 146). With theoretical coding all subcategories and categories are linked to one central/core category. This core category is the most relevant explanation to the phenomenon under study (Corbin & Strauss, 2008). Glaser & Strauss (1967) indicate that the “presentation of

the central/core category to readers can be made as an extended narrative or as a well-developed set of proportions” (p. 31).

Theoretical Saturation

Theoretical saturation occurs when gathering more data does not add any new theoretical insights and new properties to the core theoretical categories. What saturation is not is repetition of the same situations or events (Charmaz, 2006). Glaser (2001) states;

Saturation is not seeing the same pattern over and over again. It is the conceptualization of comparisons of these incidents which yield different properties of the pattern, until no new properties of the pattern emerge. This yields the conceptual density that when integrated into hypotheses make up the body of the generated grounded theory with theoretical completeness. (p. 191)




UNIVERSITY
of HAWAII
MĀNOA

Office of Research Compliance
Human Studies Program

MEMORANDUM

June 26, 2012

TO: Kim Dinsey-Read, RN, MSN
Principal Investigator
Nursing Department

FROM: 
Ching Yuan Hu, Ph.D.
Interim Director
Human Studies Program
Office of Research Compliance
University of Hawaii, Manoa

SUBJECT: CHS #20335- "A Caregiver's Decision Making Process in Remaining Engage in a Lead Follow-Up Program with a Child with an Elevated Blood Lead Level"

Under an expedited review procedure, the research project identified above was approved for one year on June 26, 2012 by the University of Hawaii (UH) Human Studies Program. The application qualified for expedited review under CFR 46.110 and 21 CFR 56.110, Category (5,7).

This memorandum is your record of the Human Studies Program approval of this study. Please maintain it with your study records.

The Human Studies Program approval for this project will expire on June 25, 2013. If you expect your project to continue beyond this date, you must submit an application for renewal of this Human Studies Program approval. The Human Studies Program approval must be maintained for the entire term of your project.

If, during the course of your project, you intend to make changes to this study, you must obtain the Human Studies Program approval prior to implementing them. Unanticipated problems that are likely to affect study participants must be promptly reported to the Human Studies Program.

You are required to maintain complete records pertaining to the use of humans as participants in your research. This includes all information or materials conveyed to and received from participants as well as signed consent forms, data, analyses, and results. These records must be maintained for at least three years following project completion or termination, and they are subject to inspection and review by the Human Studies Program and other authorized agencies.

1960 East-West Road
Biomedical Sciences Building 8104
Honolulu, Hawaii 96822
Telephone: (808) 956-5007
Fax: (808) 956-8683

An Equal Opportunity/Affirmative Action Institution

Application for New Approval of a Study Involving Human Subjects

University of Hawai'i, Human Studies Program
 Biomedical Bldg, Room B-104, 1960 East-West Road, Honolulu, Hawai'i 96822
 Telephone: (808) 956-5007

Date: 5/27/2012 _____

PI (name & title): Kim Dinsey-Read, RN, MSN _____ Email: dinsey@hawaii.edu Phone: 859-308-9915 _____

Department: _____ Department of Nursing _____

[] Faculty or Staff [x] Student - name of supervising professor: Dr. Alice Tse, PhD, APRN _____

Training in Human Subject Protection: When, where, & what? (optional) Collaborative Institutional Training Initiative (CITI) through Northern Kentucky University (as an assistant professor and faculty mentor) courses completed (2008-2010), _____

Project Title: A Caregiver's Decision Making Process in Remaining Engage in a Lead Follow-up Program with a Child with an Elevated Blood Lead Level

Proposed Sponsoring Agency: _____ Start Date: July-August 2012 _____

Complete Agency address: _____

Institutional Biosafety Committee (IBC) Review:

Researchers proposing projects involving r-DNA molecules or any biological materials, toxins, agents, etc., referred to as

biological commodities, must submit appropriate Biological Safety Program forms.

Does this project involve the use of biohazardous materials, recombinant DNA and/or gene therapy?

[] Yes. If so, Institutional Biosafety Committee (IBC) approval must be obtained.

[x] No

Has the Institutional Biosafety Committee approved the protocol?

[] Approved

[] Application Pending

(for more information check: www.hawaii.edu/ehso)

Date Approved:

Date Submitted:

1. Summarize your proposed research. Outline objectives and methods.

The purpose of this study is to generate the beginning of a substantive theory on caregiver's decision making process that determine continued engagement in lead follow-up screening. The research questions this study will answer are; 1. What are the decision making processes caregivers undergo to determine if they will remain engaged in the lead follow-up screening program?

2. What are the social contexts and processes that influence the decision making processes that caregivers undergo to determine continued engagement in a lead follow-up screening program? This study is a qualitative research study using grounded theory methodology. The data will be collected through participant observation and semi-structured interviews with probing questions and prompts to augment the interview. Information will be collected from the health department chart to determine how many visits are needed to address the child's lead poisoning, blood lead levels, case management, environmental home visit results, as well as, other health department visits such as WIC and well child, and any other pertinent data and overall health. No other protected health information from the child's medical records will be used in this research.

2. Summarize all involvement of humans in this project (who, how many, age, sex, length of involvement, frequency, etc.) and the procedures they will be exposed to. Attach survey instrument, if applicable.

This researcher will use the local and State Health Department lead logs and the assistance of the county lead case managers to access caregivers over the age of 18 and who have experienced the process or are presently under going the process of lead follow-up screening in the Northern Kentucky region. The caregiver's children must be age six or under and have had a blood lead level that was 10µg/dL or greater and have had at least two lead follow-up testing screening visits. All caregivers meeting these criteria will be contacted by letter explaining the purpose of the study along with the researcher's contact information. One week after the letter has been sent a

follow-up phone call will be made by the researcher to recruit the caregiver. Case managers may also identify potential participants in the clinic during lead follow up screening and the researcher will be present if participants would like to participate.

The researcher will meet individually with interested caregivers and explain the components on the Informed Consent and answer any questions. For this meeting, the researcher will talk with the potential participant in a private room at the Health Department clinics or at the participant's home or by phone.

Before the interview starts the participant will be informed of the purpose of the study the procedures including, signing of confidentiality and informed consent, the choice of setting and time frame of the interview. For the study, the participant choose where they are most comfortable being interviewed. This could be their home or by phone. The researcher will also have access to a private room at the Health Department clinics if the participant prefers to carry out the interview during lead follow-up appointments.

The interview will take place in an area of choice of the subject and the length of the interview will be approximately 30 to 60 minutes in length. The consent will be reviewed and read to the participant and consent will be obtained (see Appendix A). The participant will be asked to fill out a demographic data sheet with the researcher reading and assisting with this process as well (see appendix B) and the interviewee will be informed that the interview will be audio taped. Verbal consent will be obtained with the audio recorder on as well. The participant will be given a grand tour question with subsequent questions to clarify and explore themes and perceptions (see Appendix C). Additional open ended questions may be included to clarify the perspectives of the participants as the interview progresses. At the end of the interview the participant will be thanked for their time and asked if they would like the results of the research study to sent to them upon completion. Data Collection will be obtained through the use of semi-structured interviews with a question interview guide developed by this researcher after literature review, and reviewed for face and content validity by experts: 1) Quality Manager who has managed the Childhood Lead Poisoning Prevention Program (CLPPP), 2) Director of Clinical Services, and 3) Director of the District Health Department in Kentucky and 4) a participant (DeVellis, 2003).

The child's chart will also be reviewed for blood lead levels, timing between visits, case management and environmental home visit results, as well as, any other pertinent data (see Appendix D). All interviews will be audio taped with the participant's permission and field notes recorded with information such as location and length of the interview, and who else is in attendance with the participant (Wuest, 2006).

The field notes, consent forms, audiotapes, and transcripts will be locked in a drawer that only this researcher has accessibility and the key to. The loss of privacy will be discussed with the participant by indicating that any identifying information will be locked in the drawer that only the researcher has access to and codes will be used in place of identifying information (such as names of people and places) and in the event this work is published there will be not identifying information.

Check whether any subject of your research will be selected from the following categories:

- | | | | |
|------------------------------------|--|--|----------------------------------|
| <input type="checkbox"/> Minors | <input type="checkbox"/> Pregnant Women | <input type="checkbox"/> Mentally Disabled | <input type="checkbox"/> Fetuses |
| <input type="checkbox"/> Abortuses | <input type="checkbox"/> Physically Disabled | <input type="checkbox"/> Prisoners | |

3. Research involving humans often exposes the subjects to risks: For the purpose of this application, "risk" is defined as exposure of any person to the possibility of injury, including physical, psychological, or social injury, as a consequence of participation as a subject in any research, development, or related activity which departs from the application of those established and accepted methods necessary to meet his needs, or which increases the ordinary risks of daily life, including the recognized risks inherent in a chosen occupation or field or service.

a. Check all the risks to human subjects that apply to your project:

- | | | |
|--|---|---|
| <input type="checkbox"/> Physical trauma or pain | <input type="checkbox"/> Deception | <input type="checkbox"/> Experimental diagnostic procedures |
| <input type="checkbox"/> Side effects of medications | <input checked="" type="checkbox"/> Loss of privacy | <input type="checkbox"/> Experimental treatment procedures |
| <input type="checkbox"/> Contraction of disease | <input type="checkbox"/> Worsening of illness | <input type="checkbox"/> Other – explain |
| <input checked="" type="checkbox"/> Psychological pain | <input type="checkbox"/> Loss of legal rights | |

b. Check procedures that will be used to protect human participants from risks:

- ☐ M.D. or other appropriately trained individuals in attendance

- ☐ Sterile equipment
 - ☐ Precautions in use of stressor or emotional material (explain below)
 - ☐ When deception used, subjects fully informed as to nature of research at feasible time (explain below)
 - ☐ Procedures to minimize changes in self-concept (explain below)
 - ☒ Confidentiality of subjects maintained via code numbers and protected files
 - ☐ Anonymity - no personally identifiable information collected
 - ☐ Others-- explain
- c. Has provision been made to assure that Human Subjects will be indemnified for expenses incurred as a direct or indirect result of participating in this research?
- ☒ Not applicable
 - ☐ No - The following language should appear in the written consent form: ***I understand that if I am injured in the course of this research procedure, I alone may be responsible for the costs of treating my injuries.***
 - ☐ YES, explain:
- d. Are there non-therapeutic tests that the research subjects may be required to pay for?
- ☐ Not applicable
 - ☒ No
 - ☐ Yes - explain below. The following language should appear in the written consent form: ***I understand that I may be responsible for the costs of procedures that are solely part of the research project.***
4. Describe mechanism for safety monitoring: How will you detect if greater harm is accruing to your subjects than you anticipated? What will you do if such increased risk is detected?

Qualitative interviewing research is considered noninvasive and talking is considered therapeutic. As a result this study should pose no apparent physical, psychological, economical, or social risk to the participants. Participants may experience some stress reliving the experience of having a lead poisoned child, or guilt in the consideration of not returning for lead follow-up screening. The participant may also experience stress or fear if they indicate the program has not met the needs of their lead poisoned child or indicate poor performance of a Health Department employee. The participant will be made fully aware that any information given to the researcher would no way impact on the benefits that they are provided by the Health Department. The interviewer (a Registered Nurse) will assess the emotional demeanor of the participant and provide contact cards, pamphlets and a referral to the local mental health agency for follow up and support (Munhall, 1993). To protect against psychological risks the subjects will be informed: 1) their participation is entirely voluntary, 2) they are free to refuse to participate and to withdraw from the study or any portion of the study and, 3) they have the right not to answer any question that they feel uncomfortable with.

5. Briefly describe the benefits that will accrue to each human subject or to humankind in general, as a result of the individual's participation in this project, so that the committee can access the risk benefit/ratio.

There will no direct benefits to the participant but this study and their participation will add knowledge to the treatment of lead poisoning children and their families and help to increase the knowledge base of health care professionals who work in public health. Serving in this capacity might in fact increase the participant's self esteem.

The participants will be given a gift card for \$ 15.00 from a grocery chain at the interview and their name will be added in for a drawing for a \$100.00 gift certificate. If the participants chooses not to complete the interview they will still receive the gift card and an opportunity to participate in the drawing. The outcomes of the study will be shared with any participant who is interested in receiving the results.

6. **Participation must be voluntary: the participants cannot waive legal Rights, and must be able to withdraw at any time without prejudice.** Indicate how you will obtain informed consent:

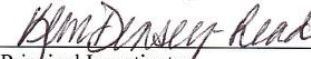
☒ Subject (or Parent/Guardian) reads complete consent form & signs ('written' form)

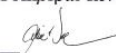
- ☐ Oral briefings by PI or project personnel, with simple consent form ('oral' form). Explain below the reason(s) why a written consent form is not used
- ☐ Other- explain

7. Are there any other local IRB's reviewing this proposal? ☒ No ☐ Yes, Location: _____

I affirm:

- (i) *that the above and any attachments are a true and accurate statement of the proposed research and of any and all risks to human subjects.*

Signed:  Date: 5/31/2012
Principal Investigator

Signed:  Date: 5/31/12
Supervising Professor (required if PI is a student)

Digitally signed by Alice Tse
DN: cn=Alice Tse, o=UH,
email=atse@hawaii.edu, c=US
Date: 2012.05.31 19:04:32 -1000

* Submit an electronic (.doc or .pdf format preferred) copy of this application form with the following attachments:

- Consent form(s)
 - Any other information to be read or presented to the study participants
 - Verbal information to be given if short form (consent)
 - Survey instrument(s) (Please consult with the Human Studies Program staff if providing the survey instrument is a problem.)
 - Proposal/Protocol (If appropriate. Do not attach a grant application or a contract.)
- By email to uhirb@hawaii.edu

* In addition to the email submission, mail or deliver 3 hard copies (collated) to:
(UH Human Studies Program, UH Manoa Campus, 1960 East-West Road - Biomed B-104, Honolulu, HI 96822)

This is for proposals needing full Committee or expedited review. If this is a project that may qualify for exempt approval, hard copy is not required; the email submission will be sufficient. Please check with Human Studies Program staff if you have questions about the level of review of your proposal.

Appendix C

Informed Consent for participation in A Caregiver's Decision-Making Process in Remaining Engage in a Lead Follow-up Program with a Child with an Elevated Blood Lead Level Principle

Investigator: Kim Dinsey-Read RN, MSN,
School of Nursing, PhD Program
University of Hawai'i
Honolulu, HI, 96822

The purposes of this project are:

1. To fulfill a dissertation requirement in the PhD program, at the University of Hawai'i.
2. To try to understand what thoughts caregivers have about returning for follow-up lead screening so that the public health nurse can improve the care that they give to children in an effort to impact on lead poisoning.

Participant Selection:

You were chosen for this study because of the experiences you have with taking care of a child for at least 2 follow-up screening appointments and living in the Northern Kentucky region.

Voluntary Participation and Right to Refuse:

1. Your participation is entirely voluntary
2. You are free to refuse to participate and to withdraw from the study or any portion of the study.
3. You have the right not to answer any question that they feel uncomfortable with.
4. If you decide not to participate or withdraw from the study, it will not jeopardize your relationship with the Health Department or any health provider.

The methods to be used to collect information for this study are explained below. From this information, I will write the research study:

I would like to interview you in a location that you are comfortable with and you have chosen so that you can talk openly about your experience as a caregiver with lead screening. I will audiotape the interview and will try to place the tape recorder in a place that will be the least distracting. If you do not wish to answer a question you may say so and I will move onto the next question. No one else will be present unless you want someone with you. The information recorded is confidential and no one will have access to it except me, and the faculty assisting me in this research study. Your name or the names of others will not be used in the information. Everything you say will be typed into a transcript and I will try to look for similarities between your experiences with those of other caregivers with children with elevated lead and follow-up screening. I will use the information from this study to write the research study. It may be

published in professional journals and presented to the Health Department staff so that others can benefit from the knowledge that you have shared with me.

With your permission I would also like to review your child's chart. The information I will be recording for my research will be limited strictly to how many times you had to come for lead testing, if a case manager visited or called you, if an environmentalist did an assessment or your home, how many times did you use the Health Department for other services such as WIC or immunizations. I also will be looking at if at any time you choose not to come back to the Health Department and if they tried to contact you. Overall what I am trying to see is how many visits you needed to address your child's lead poisoning and overall health. No other protected health information from your child's medical records will be used in this research.

You are encouraged to ask any questions at any time about the nature of the study and the methods that I am using. Your suggestions and concerns are important to me; please contact me at any time Kim Dinsey-Read (859)-308-9915 or the Committee on Human Studies, University of Hawai'i, and 2540 Maile Way, Honolulu, HI 96822. Telephone: (808) 956-5007.

Risks and Discomforts:

There is the risk that you may share some personal or confidential information that may make you feel uncomfortable. If you do not wish to share this type of information you do not have to answer questions or participate in the interview if you feel the questions are too personal or make you feel uncomfortable.

Benefits:

There will no direct benefits to you, but your participation will add to the knowledge that healthcare providers have and will assist in the treatment of lead poisoned children and help increase the education of their families. Some people may find it helpful to share their experiences with others. For your participation you will receive a \$15-dollar grocery gift card and your name will be entered a random drawing for a \$100-dollar grocery gift card.

Confidentiality:

All information that is collected will be kept private and locked in a draw with a lock and key. All information will have a number code on it. No names will be connected to the experiences you share. I am the only person that will know your number and name.

Sharing Results:

If you wish you may have the results from the study and you can receive a summary of the study before it is published. The results will be published so that other healthcare providers can learn from this research study.

Certificate of Consent:

I have been invited to participate in the research study titled *Caregiver's Decision-Making Process in Remaining Engage in a Lead Follow-up Program with a Child with an Elevated Blood Lead Level* and I will be interviewed by the researcher. The researcher has informed me that the risks are minimal and that my participation is voluntary, that I have the right to withdraw at any time or refuse to answer questions that make me feel uncomfortable. I am aware that there will be no benefits to me personally.

Do you grant permission to be quoted directly without being named?

Yes _____ No _____

Do you grant permission to be audio taped?

Yes _____ No _____

Do you grant permission to allow me to review your child's chart at the Health Department?

Yes _____ No _____

Do you grant permission me permission to re-contact you if I have any further questions or want to see how you are doing with the follow-up process?

Yes _____ No _____

Do you wish a summary of the results? Address _____

Yes _____ No _____

Print name of participant _____

Signature of participant _____ Date _____

I have accurately read or witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely (World Health Organization Research Ethics Review Committee, 2005, 4)

Print name of researcher _____

Signature of researcher _____ Date _____

A copy of this Informed Consent Form has been provided to the participant _____ (initialed by the researcher)

Please contact Kim Dinsey- Read (859-308-9915) if you have any questions regarding this project. If you cannot obtain satisfactory answers to your questions or have comments or complaints about your treatment in this study, contact: Committee on Human Studies, University of Hawai'i, and 2540 Maile Way, Honolulu, HI 96822. Telephone: (808)-956-5007
uhirb@hawaii.edu

Appendix D

Appendix D

Interview Question Guide

1. Would you please share with me what it was like for you to have a child with an elevated lead level?
2. Could you tell me your story from the beginning of when your child was first tested for lead exposure?
3. Can you share with me your thoughts the first time you heard your child had an elevated lead level?
4. Can you share with me your thoughts and feelings about when you hear the words lead follow-up screening?
5. What things do you think about when deciding to attend lead follow-up screening?
6. Please share with me what the follow-up appointments are like for you?
7. At any point did you think that the follow-up lead screening was not necessary? If so why?
8. At any point did you considered not returning for the follow-up testing? If so why?
9. What helped you to continue with your follow-up appointments?
10. What made it hard for you to continue with your follow-up appointments?

Questions added as the interviews progressed

11. Was there anyone, anything or any situation that gave your strong emotions?
12. At any point did you consider not returning for WIC appointments?
13. Were there relationships that helped you with lead follow-up screening?
14. How do you make decisions about healthcare for yourself?
15. How is decision making for health care different for you versus your child?
16. How do you make other important decisions?
17. How are these decisions different than health care decisions that you make for your child?
18. Do you think it is a parent role to deal with lead poisoning and lead follow-up screening?

19. What about the community or society do you think they have a responsibility to assist with lead poisoning and lead follow-up screening?
20. Do you think it is a nurse's and/or doctor's role to deal with lead poisoning and follow-up screening?
21. Do you get to make choices about your lead case management and lead follow-up screening?
22. Tell me about the choices you make about lead case management and lead follow-up screening?
23. What makes you successful at managing your child's lead levels and lead follow-up?

Appendix E

Chart Information

1. Case Management Home visit: Yes_____ No _____
2. How long ago? _____ (weeks)
3. Follow-up phone contact: Yes_____ No_____
4. How many follow-up phone contacts_____
5. Number of clinical visits for LFS._____
6. Number of clinical visits for WIC. _____
7. Number of clinical visits for Immunizations_____
8. Number of clinical visits for Early Well Child Screening Diagnostic Prevention
visit_____
9. Number of clinical with combined purpose visits (i.e. WIC, EWCSDP, Immunizations, and
LFS) _____
10. Environmental Risk Assessment completed on the home? Yes_____ No_____
11. Follow-up phone call or contact made by environmental department? Yes_____ No_____
12. Any of these calls for failure to return for follow-up? Yes_____ No_____
13. Contact made? Yes_____ No_____
14. Letters sent? Yes_____ No_____
15. Certified Letter sent? Yes_____ No_____
16. Was this case lost to follow-up? Yes_____ No_____
17. How was contact made with caregiver to re-engage contact?

18. Contact made from the State of Kentucky CLPPP program to caregiver? Yes_____ No_____

19. Missed appointments? Yes_____ No_____

20. How many missed appointments? _____

21. Any information in chart that would indicate pending issues, dissatisfaction, insufficient results, issues with the child, WIC, long waits, etc....

specify_____

Appendix F

Participant ID: _____

A. Demographic Information

A1. Your age: _____ years

A2. Gender (mark one): _____ Male _____ Female

A3. Your marital status (mark one): _____ Single _____ Married/Partnered

A5. Your race/ethnicity (check one):

_____ African- American _____ Asian _____ Hispanic _____ White
_____ Appalachian _____ other (please specify) _____

A6. Your highest education degree achieved (mark one):

_____ Less than High school _____ High school _____ Some College _____ College
_____ Master/Doctorate _____ other professional degree (please specify) _____

A7. Household Income (mark one):

_____ less than 5,000 per year
_____ 5,001 to 10,000 per year
_____ 10,001 to 15,000 per year
_____ 15,001 to 20,000 per year
_____ 20, 0001 to 25,000 per year
_____ 25,001 to 30,000 per year
_____ 30, 0001 to 35,000 per year
_____ 35, 0001 to 40,000 per year
_____ 40,001 to 45,000 per year
_____ 45, 0001 to 50,000 per year
_____ 50, 0001 to 55,000 per year
_____ 55,001 to 60,000 per year
_____ 65, 0001 to 70,000 per year
_____ 70,001 per year or more

A8. Do you use Women, Infant, and Children Nutritional Services (WIC)? _____ Yes _____ No

A9. How old do you think the building you live in is? _____ Years

A10. For the building that you live in do you? (Mark one):

A10. For the building that you live in do you? (Mark one):

_____Rent _____Own_____Visiting

A11. How many children are living in your home? _____number of children

A12. How many children have had verified elevated lead levels? _____number of children

A13. Please indicate the age of the child and their lead level when first tested and how many times you think they had to be re-tested.

Child	Age of Child	First Lead Level	Number of Retests
Child 1			
Child 2			
Child 3			
Child 4			
Child 5			
Child 6			
Child 7			
Child 8			

A14. Was your child's elevated lead from your home?

_____Yes _____No

If you checked 'No' what was the other source for example (grandparents, neighbors, or babysitter' homes, work related exposure, toys...) _____.

(Please list the lead source)

Appendix G

Respondent Interview Questionnaire Results

Caveats

The number of respondents for some categories is very small. Also, reported percentages in some instances are based on small ns. Therefore, the statistics reported should be interpreted with caution. Column percentages may not total to 100 due to rounding. Where appropriate, the mean and standard deviation (SD) are included in the text below but not in a table.

Results

Overall, 16 individuals completed the survey, and in most cases, the respondents indicated one participant (86 percent). Among participant #1s, the majority were females (86 percent), and the overall age ranged from 23 to 56, with the average age being 33 years old. There were only two participant #2s, which were both male; one was 25 years old and the second was 45 years old.

A0. Number of participants		
	n	%
1	14	87%
2	2	13%
Total	16	100%

A2a. Gender participant # 1

	n	%
Male	2	14%
Female	14	86%
Total	16	100%

A1a. Your age in years? Participant # 1

	n	%
23	2	14%
24	1	7%
25	2	14%
26	2	14%
27	1	7%
36	1	7%
43	1	7%
46	1	7%
55	1	7%
56	1	7%
DNA	1	7%
Total	14	100%

A1b-A2b. Participant # 2 age and gender

	Male	
	n	%
25	1	50%
45	1	50%
Total	2	100%

Note: N/A is excluded from the above analysis.

Respondents were also asked to complete several other demographic questions. Overall, nearly six out of 10 respondents each said they were married/partnered (57 percent) and white (57 percent). Additionally, half completed high school or less than high school (50 percent). Household income was spread across multiple categories, but the largest concentration of responses fell under less than \$5,000 per year (36 percent). With the exception of one person, all of the respondents use Women, Infant, and Children Nutritional Services (WIC) (93 percent).

A3. Your marital status		
	n	%
Single	5	36%
Married/Partnered	8	57%
DNA	1	7%
Total	14	100%

A4. Your race/ethnicity		
	n	%
African American	4	29%
White	8	57%
Other	1	7%
DNA	1	7%
Total	14	100%

Note: The other specified race/ethnicity is Arabic.

A5. Your highest education degree achieved?		
	n	%
Less than high school	2	14%
High school	5	36%
Some college	4	29%
College	3	21%
Total	14	100%

A6. Household income		
	n	%
Less than 5,000 per yr.	5	36%
5,001-10,000 per yr.	1	7%
10,001-15,000 per yr.	3	21%
15,001-20,000 per yr.	2	14%
20,000-25,000 per yr.	1	7%
DNA	2	14%
Total	14	100%
A7. Do you use Women, Infant, and Children Nutritional Services (WIC)?		
	n	%
Yes	13	93%
No	1	7%
Total	14	100%

When asked about the respondent's residence, 57 percent said their building was less than 100 years old, and on average, the building was 76 years old (SD = 39.2). Most indicated that they rent their home (71 percent).

A8. How old do you think the building you live in is? (in years)		
	n	%
Less than 100 years		
1	2	14%
48	1	7%
50	1	7%
58	1	7%
82	1	7%
90	1	7%
93	1	7%
Less than 100 years Total	8	57%
100 years or older		
100	4	29%
111	1	7%
130	1	7%
100 years or older Total	6	43%
Total	14	100%

A9. For the building that you live in do you?		
	n	%
Rent	10	71%
Own	4	29%
Total	14	100%

On average, there were three children living in the home ($SD = 1.7$), and most respondents reported that one child had a verified elevated lead level (86 percent). The elevated lead levels primarily originated from the current home (43 percent) or previous home (50 percent).

A10. How many children are living in your home?		
	n	%
1	5	36%
3	3	21%
4	2	14%
5	4	29%
Total	14	100%

A11. How many children have had verified elevated lead levels?		
	n	%
1	12	86%
2	2	14%
Total	14	100%

A13. Was your child's elevated lead from your home?		
	n	%
Yes	6	43%
No	6	43%
Not sure	2	14%
Total	14	100%

A14. If no name other source

	n	%
Another place outside in the dirt	1	17%
Homeless shelter they lived in	1	17%
Pottery and makeup from native country	1	17%
Previous house	3	50%
Total	6	100%

Note: The above analysis represents those that said their child's elevated lead was NOT from their home.

Among the 15 children reported, on average, the children's lead level was first tested at age 31 months (SD = 11.0). The average first lead level reading was 10.1 (SD = 8.0), and the average highest lead level was 14.2 (SD = 7.5). Respondents reported about six retests (average = 5.9, SD = 2.9).

A1B12. Age of child (months) when lead level first tested

	n	%
12	1	7%
17	1	7%
22	2	13%
24	3	20%
36	5	33%
42	1	7%
48	2	13%
Total	15	100%

Note: The total reflects the aggregate number of children reported by the respondents in the survey.

A1B12. First lead level

µg/dL	n	%
2.5	1	7%
3.3	1	7%
5.0	1	7%
5.6	1	7%

5.8	1	7%
7.2	1	7%
7.9	1	7%
8.1	1	7%
10.0	2	13%
10.8	2	13%
12.0	1	7%
17.0	1	7%
35.6	1	7%
Total	15	100%

Note: The total reflects the aggregate number of children reported by the respondents in the survey.

A1B12. Highest lead level

	n	%
5.5	1	7%
6.4	1	7%
9.3	1	7%
10.0	1	7%
10.5	1	7%
10.8	1	7%
12.0	1	7%
12.1	1	7%
12.2	1	7%
13.0	1	7%
17.0	1	7%
18.0	2	13%
23.0	1	7%
35.6	1	7%
Total	15	100%

Note: The total reflects the aggregate number of children reported by the respondents in the survey.

A1B12. Number of retests

2	1	7%
3	2	13%
4	4	27%
6	1	7%

7	2	13%
8	4	27%
13	1	7%
Total	15	100%

Note: The total reflects the aggregate number of children reported by the respondents in the survey.

Appendix H Case Management Chart Review

The next series of questions look at case management. In general, the vast majority of the chart reviews indicated that the participant's case was still open (79 percent) and that they have received a home visit (93 percent). There was a wide variation in the length of time in case management, ranging from four weeks to 157 weeks, but the average duration was 65.5 weeks or roughly 15 months (SD = 51.7). Most notable, about four out of 10 respondents (43 percent) said they had been in case management for more than a year and a half (88 weeks or more).

B1. Status of the case?		
Open	11	79%
Closed	3	21%
Total	14	100%
B2. Case management home visit?		
Yes	13	93%
No	1	7%
Total	14	100%
B3. How long in case management? (in weeks)		
4-53 weeks		
4	1	7%
12	2	14%
18	1	7%
24	1	7%
40	1	7%
52	1	7%
53	1	7%
4-53 weeks Total	8	57%
88-157 weeks		
88	1	7%
96	1	7%
103	1	7%
106	1	7%
152	1	7%
157	1	7%
88-157 weeks Total	6	43%
Total	14	100%

In terms of follow up, most participants had a follow-up phone contact (86 percent), and of those, there were four follow-up phone contacts on average (SD = 2.7).

B4. Follow-up phone contact?		
Yes	12	86%
No	2	14%
Total	14	100%
B5. How many follow-up phone contacts?		
1	3	25%
2	2	17%
3	2	17%
5	2	17%
6	2	17%
10	1	8%
Total	12	100%
Note: The above analysis represents those that said there was a follow-up phone contact.		

The largest proportion of participant each had 0-2 clinical visits for LFS (average = 2.1, SD = 2.0) and two clinical visits for WIC (average = 4.9, SD = 3.0). In contrast, most participants did not have any visits for immunizations (average = .9, SD = 1.8) or clinical visits for Early Well Child Screening Diagnostic & Prevention (EWCSDP) (average = .4, SD = .9). Results were mixed for clinical visits for combined purposes, LFS, WIC, IMM, and EWCSDP (average = .6, SD = .6).

B6. Number of clinical visits for LFS?		
0	3	21%
1	4	29%
2	3	21%
3	1	7%
4	1	7%
6	2	14%
Total	14	100%
B7. Number of clinical visits for WIC?		
2	5	36%
3	1	7%
4	2	14%
6	1	7%
7	2	14%
8	2	14%
11	1	7%
Total	14	100%
B8. Number of clinical visits for immunizations?		
0	9	64%
1	3	21%
5	2	14%
Total	14	100%
B9. Number of clinical visits for Early Well Child Screening Diagnostic & Prevention (EWCSDP) visit?		
0	10	71%
1	3	21%
3	1	7%
Total	14	100%
B10. Number of clinical visits for combined purposes, LFS,		

WIC, IMM, EWCSDP?		
0	6	43%
1	7	50%
2	1	7%
Total	14	100%

For environmental risk assessment, 64 percent of the participants did not have one completed on their home. Additionally, in general, there had not been a follow-up phone call or contact made by the environmental department (93 percent). About 60 percent of the participants received calls for failure to return for follow-up. In most cases, contact had been made (73 percent), and in all cases, a letter had been sent (see table B15O for types of letters). However, most often, the letter had not been sent certified (62 percent). As reported by 11 out of 13 participants (85 percent), the case had not been lost to follow-up. Table B18 includes the verbatim methods for re-engaging contact with caregivers.

B11. Environmental Risk Assessment completed on the home?		
Yes	5	36%
No	9	64%
Total	14	100%
B12. Follow-up phone call or contact made by environmental department?		
Yes	1	7%
No	13	93%
Total	14	100%
B13. Any calls for failure to return for follow-up?		
Yes	8	57%
No	6	43%
Total	14	100%
B14. Contact made?		
Yes	8	73%
No	3	27%
Total	11	100%
Note: N/A is excluded from the above analysis.		

B15. Letters sent?		
Yes	13	100%
Total	13	100%
Note: N/A is excluded from the above analysis.		
B15O. What type of letters		
MA-missed appointment	3	23%
I-Information	2	15%
LFU	2	15%
NR-not returning	2	15%
RL-reminder letter	1	8%
DNA	4	31%
Note: The above analysis represents those that said a letter was sent (n=13). Responses do not sum to 100% due to multiple choices.		
B16. Certified Letter sent?		
Yes	5	38%
No	8	62%
Total	13	100%
Note: The above analysis represents those that said a letter was sent.		
B17. Was this case lost to follow-up?		
Yes	2	15%
No	11	85%
Total	13	100%

B18. How was contact made with caregiver to re-engage contact?
Contacted family cabinet services re: medical neglect. Now going to the children's lead clinic.
Lead case manager met them at children's clinic, called and phone not working, reminder cards sent so would not miss appointments.
Letter
Letters, visit phone calls, threatened medical neglect, faxed primary provider and Children's Hospital.
No show appointments, 5 rescheduled, indicated cancelled or did not show because of behavior of child, Lead case manager is meeting family at clinic for blood draws.
One no show appointment, took child to lab, but no order, RN forwarded order to lab.

Phone calls, voice mails, reminder cards, faxed script to lab so parent could take child.

Referred to cabinet family services for medical neglect.

About eight out of 10 participants (79 percent) contact was not made from the State of Kentucky CLPPP program to the caregiver. Most participants missed one appointment (67 percent). Refer to table B22 for the verbatim responses regarding information in the chart about pending issues, dissatisfaction, insufficient results, issues with the child, WIC, long waits, etc.

B19. Contact made from the State of Kentucky CLPPP program to caregiver?		
Yes	3	21%
No	11	79%
Total	14	100%
B20. Missed Appointments?		
Yes	9	64%
No	4	29%
DNA	1	7%
Total	14	100%
B21. How many missed appointments?		
1	6	67%
2	2	22%
5	1	11%
Total	9	100%
Note: The above analysis represents those that said yes to missed appointments question.		

B22. Any information in chart that would indicate pending issues, dissatisfaction, insufficient results, issues with the child, WIC, long waits, etc.... specify

Blood was collected in wrong tube at lab so had to be drawn again.

Cannot do Well Child as the child has sickle cell anemia.

Child's behavior is very challenging.
Father handled most the visits the child attends due to the mother being disabled after an accident so many times it was due to her inability, parents are separated.
Goes to Children's for all appointments.
Mother had to insist on re-testing child and home inspection was denied.
Transportation set up for next visit.
Very cooperative, paternal grandparents have custody for one year, grandparents reported to nurse that child had elevated lead level from primary care visit.

Appendix I: Memo Examples

Memo 1

Illustrates open coding of the data a using who, what, when, where, how and why.

The participant found discovering her child was lead poisoned was very difficult, she felt guilty and sad and worried about her child's wellbeing and future. Caregiver indicated she did not want this for her daughter's future. The participant describes lead case management and LFS process. The caregiver discussed that the "multiple pokes" were very rough. Caregiver indicated that she felt very protective towards her daughter "felt why not me, instead of her". Caregiver returned for LFS because she did not want to upset the nurse and she did not want her daughter to be like her cousin who had brain damage from lead poisoning. The caregiver indicated the lead nurse cared about her and her daughter. The caregiver indicated it is the role of the parent to act so continued to take her to LFS. The case is now closed after four years and the caregiver indicated she felt very accomplished and happy!

Who	What	When	Where	How	Why
Caregiver and the Lead Nurse	LFS and Case management Very difficult, felt guilty and sad	4 years during daughter's ELL.	Child's living environment, the house interior, and specifically the dirt surrounding the house.	Relationship with Lead Nurse. Help with transportation.	Did not want her child to have brain damage from lead poisoning like her cousin. Caregiver continuing to go to LFS and manage lead hazards as her role as mother.

In- Vivo Special/Social Words: Multiple pokes or finger pokes –process of acquiring capillary sample from the finger. Need to get un-clotted blood and fill up a pipette or paper. Often requires multiple sticks and often the sample is contaminated to it comes back high or insufficient which requires a repeat of the process.

Memo 2 is an example of the analytical thinking involved in considering the concepts involved in the study.

Psychological Reactions: Long Term Anxiety, Fear, Guilt and stigma.

Caregiver indicated lead poisoning was frightening and scary and she did not know what to do. She indicated she did all the things they suggested and the next test was even higher. Then they had the house tested. There appears to be a disconnect in policy and clinical practice. Again this is an example of where the child is being used as the lead alarm. The lead level has to reach a certain level for case management. Next the lead level has to reach the level where the house can be tested which is higher than case management. This means the time period between first level to second is an educated guess where the hazards are versus knowing where they actually exist. Seems that this practice would only increase the parent's anxiety about being able to manage the child's lead levels. Caregiver had to wait to save up for the funds to fix their home as they owned the property. As a result, the family had to live in the very place that was causing their child's sickness. These parents are essentially stuck. Caregiver found it frightening very concerned with the lead being so high in his body. She just wants it out and feels he is very smart and does not want him to be impacted long term with learning disabilities. "My emotions have been all over the place the entire time." Finding out about the lead poisoning appeared to create a psychological trauma to this caregiver and continues to create worry and anxiety for this mother. During this very vulnerable time she indicates that she felt threatened and attacked when the nurse indicated if she did not comply she would lose custody of her child. It appears this further traumatized her and contributed to the disintegration of her relationship with the Health Department (Participant 6).

Memo 3 is an example of the analytical thinking involved in considering the concepts involved in the study.

The caregiver did not take the child back for LFS as the parent did not think it was that important. The child was not sick, the Health Department did not come to the house. When she found out she could be charged with medical neglect she said she knew it was important then. She was given more information and had a better understanding of why it was important but still questions lead follow-up screening. She knows sometimes parents are lazy but she doesn't really see what is beneficial about it. She did indicate it helps her to know if the changes she made are helping or not "If we did something right". Again appear more like going through the motions as she is not totally sure what makes a difference. Returning for LFS because she has to legally and when she talks about going back it sounds almost like a ritual of good luck. Parents incur significant psychological reactions when they are informed or threatened with medical neglect. They do not appear to fully understand this risk nor the importance of follow-up. There is a disconnect in the policy that BLL initiates case management and the level that initiates the environmental assessment on this house to identify lead hazards. The inference this caregiver made was that the Health Department did not come to the house so lead poisoning must not be that important (Participant 3).

Memo 4 is an example of the analytical thinking involved in identifying the theoretical concept of *Caregiver Coping*.

Caregiver Coping: Doing, and Relationships & Supports, Family in Poverty

Caregiver indicated they are just surviving as a family. Just had the electricity shut off and she had just returned to get it turned back on. Husband was laid off and they were homeless before they moved into this house. Short term survival needs are definitely overshadowing the long term concerns of their daughter's health and the impact of lead. If this family had nowhere to live and do not have electricity it is hard for them to focus on doing what is necessary for lead follow-up screening and case management. It should be noted that the mother is not from the United State but her husband is. She is from South Africa, College educated and fluent in English but indicated she struggles to navigate our system here as she is not used to it. Her husband is a veteran who is struggling to re-establish himself after deployment and discharge from the military. Just like other participants many seem to be trying to survive day to day with multiple issues they are trying to manage. Most of these families make less than 5,000 per year, this one included, meaning they are dependent on the system for many benefits which is not very responsive and takes a great deal of the caregiver's time to connect with. Engagement is not likely under these circumstances Participant 3).

Memo 5 is an example of the analytical of the concept of Psychological Reactions.

Psychological Reactions: Long term fear, anxiety, guilt and stigma.

The caregiver discussed her feeling that represented stigma she felt as judged, talked down to and felt that the Health Department staff thought that she was not clean. The caregiver saw her role as ensuring the children was healthy. Again because lead is found in dust and the interventions taught to caregivers involve cleaning and managing dust caregivers extrapolate from this that they are dirty and are feel judged. This train of thought appears to have serious consequences to the therapeutic relationship with the lead nurses who help to support caregivers in these activities. This caregiver has chosen to go to Children's Hospital and not return to the Health Department. Access would be an issue for communities without a second option for lead treatment. For other families in this study transportation is a significant barrier so accessing another source is not an option. The perceptions of caregivers and management of the guilt and stigma needs to be addressed for best possible outcome for the child (Participant 5).

Memo 6 is an example of analysis of Meeting Expectations. This also looks at the variation in experiences.

Meeting Expectations: Caregiver role and social expectations & Health care and System expectations.

Caregiver described it as her duty as a parent to take care of her daughter. She actually asked to have her child retested at WIC although her lead had gone down. She was denied as the child's lead was down even though she had been previously lead poisoned and was at risk as per the guidelines. Caregiver pursued this and determined she could have the child tested under Medicaid policy 4 times a year because of her risk factors. Really had to push to get this done and had her pediatrician contact the Health Department to indicate this mother could have the child tested as per the guidelines. The re-test was high and caregiver was very upset because if she had taken the refusal the child would have been lead poisoned without intervention. The elevated level now allowed for her home to be tested and determine the source of lead as well as receive more education and information. Again there seems to be a disconnect between actual practice and policies, guidelines and the best practice to address lead poisoning. The parent worked around multiple systems to get what she needed from WIC, Health Department and used her provider as an ally. Not many parents who have lead poisoned children are savvy enough to navigate this system to this level. She was also able to advocate in a manner where she was heard and respected. There seems to be a disparity between parents who understand the system and those who don't. Again the difference in skills allowed for the actual engagement of the caregiver who is able to navigate the system, advocate for herself or understand the hidden middle class rules versus poverty rules (Participant 4).

Mother indicated she feels very bad that she did not take care of her son well enough and that he was lead poisoned. She feels sad that she was "irresponsible and not a good mom". Many of the symptoms that she describes sounds like she has exhaustion and potentially depression. Her son is very hyper, has sleep problems, stays up until 1:00 a.m., and does not talk. She also discussed the stigma of lead and feeling embarrassed when they came to perform lead abatement and cleaning on the house. All the neighbors wanted to know about why the sign "danger zone" was placed outside their house and they had to leave the home while it was being abated and cleaned. She indicated to me that she is looking for help with her son. She would like a referral to a doctor that could address his behavior. She has indicated she has asked for this referral many times. She admitted she did not take him for LFS but she was just so tired she made the choice not to. The caregiver came across as recognizing she had exhausted all of her coping strategies with this situation and was asking for professional help (Participant 12).

Such as difference in empowerment and engagement between these two caregivers. Their situations are so very different. One of the caregiver is a minority, exhausted and is displays symptoms of depression. She is an immigrant and English is her second language. Her son's lead level is very high and she has been in treatment with him for a long time. She openly admits she choose at one point to not take her son for LFS. The other parent indicated she knows how to navigate the system and appears to have more financial and emotional resources. She has access to extended family for assistance as well. Multiple resources are a significant facilitator for being able to adequately address their child's ELL.

Who	What	When	Where	How	Why
Caregivers	Caregivers able to navigate the system and advocate for what they need depends significantly on managing psychological reactions and caregiver coping	During the time their child has a ELL	Child's home	Control of psychological reactions, Caregiver Coping -use of Family/relational support -knowledge -doing	To be able to fully engage in LFS and mitigating the risk of lead exposure.

Memo 7 is an example of the questions asked in order to fully develop concepts

Development of the concept of Meeting Expectations versus Engagement

The caregivers indicated that when you go the doctor you expect results that is how decisions are made. Get results from the tests and gives you something to work from. A very concrete way of looking at how health care decisions are made. Bad results or opposite results than what you expected make you reconsider the treatment. The process of health care decision making with lead poisoning does not necessarily apply. For lead poisoning it is not that straight forward as often parents are not sure where or what the lead hazards are. So what these parents understand to be the process may not work with lead poisoning. It makes sense that after while everything you think will work, lead testing, cleaning, taking to appointments might seem not to help so you reconsider treatment.

Making decisions for one self is different from making them for your child. This father has been a sick child and has had a lot of experience with the health care system so is more savvy then many of the participants I spoke to. At one point a decision was made not to take this child back to LFS which resulted in reporting of medical neglect. Both parents both indicate they know LFS is important. I feel that the parents are attending LFS as they did not wish to get in trouble and lose custody of their child, not necessarily because they are engaged in the treatment process. Indicated that often health decisions are made because the individual just “wants relief”.

Caregivers indicate it is a moral responsibility to care for child, it is a parent responsibility and an “emotional sacrifice”. Stated the child is sick and the parent suffers. So sees this as a blow to the parent wellbeing. Caregivers also Indicated they do not see lead poisoning as a community issue but as a parent obligation. I found this interesting so even though the house they rented and lived in poisoned their child they saw their child’s illness as their responsibility. I wonder if this is one reason they are less likely to reach out for help and try to work through this alone. Might also be another reason they do not see the need to always follow up with LFS. They are meeting their expectations or society’s until the system required them to meet the system’s expectations. I would say that this is not engagement in treatment (Participant IR).

Memo 8: Inductive versus deductive approaches

Deductive reasoning It seems like the process of remaining in LFS would follow the pattern of hearing about the child's diagnosis, having some kind psychological response, learning about lead poisoning and its management and actively engaging in case management and LFS. The management of *psychological responses* appears to be of pivotal importance in order for the caregiver to engage in *caregiver coping*. *Caregiver coping* is impacted by psychological reactions and even some dimensions of *caregiver coping* such as *vigilance* appears to contribute to psychological reactions. It appears that psychological reactions from a nursing perspective needs to be understood and addressed as it will impact the ability of the caregiver to fully participate in *caregiver coping* and *meeting expectations*. The assumption that this is a linear process is not the case. It is very much a cyclic process and even when a caregiver appears to be engaged this can change as well as their psychological reactions. Thus it needs to be an inductive process with better understanding of the potential impact of all factors and that this is not static.

Discussing LFS

Interviewer: "You seem distressed by it".

Participant 5- "Yeah, I can't –I have to let my mom take him in because every time- I went in there- the first time, I broke down cryin.....it tears my heart out knowin' that I can't do anything about it."

Memo 9: Analytic discussion concerning implications for results of nursing practice

It appears as though there is a disconnect between what is expected of caregivers from health professionals in LFS and case management. Many treatments for children are voluntary at the discretion of parents. Even interventions that impact on the public wellbeing have become negotiable i.e. immunizations. Certain diseases are more serious than others so it is common for caregivers to follow the advice of their health professional and seek treatment i.e. cancer. Diseases that may result in mortality or significant morbidity, illicit fear and sympathy from society especially for children. These illnesses are often subsidized by organizations, such as Cancer Society, Ronald McDonald House, and St. Jude and there is an attempt to lessen the burden of disease treatment. Caregivers, whose children have lead poisoning, at first did not perceive it as serious, their children did not appear sick, the treatment regimen is not typical of other illnesses, and depending on the BLL the Health Department may or may not inspect the home. The population mostly impacted by lead poisoning, are disadvantaged families with the least number of financial, emotional and social resources. Caregivers were often surprised that case management and LFS was mandatory. Serious diseases such as cancer have a great deal more resources and supports available for parents to help educate and ensures adequate means are leveraged for continued engagement and the best possible outcome. Investigation of a more supportive LFS and case management process are needed. Public health funding is less than robust so innovative ways to provide continued support is also important. Clearer understanding on how to handle mandatory treatment expectations in practice is essential not only for continued engagement but the therapeutic alliance of caregiver and health professional which also impacts on health outcomes.

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